End-of-life care in general practice in the Netherlands

Borgsteede, S.D.

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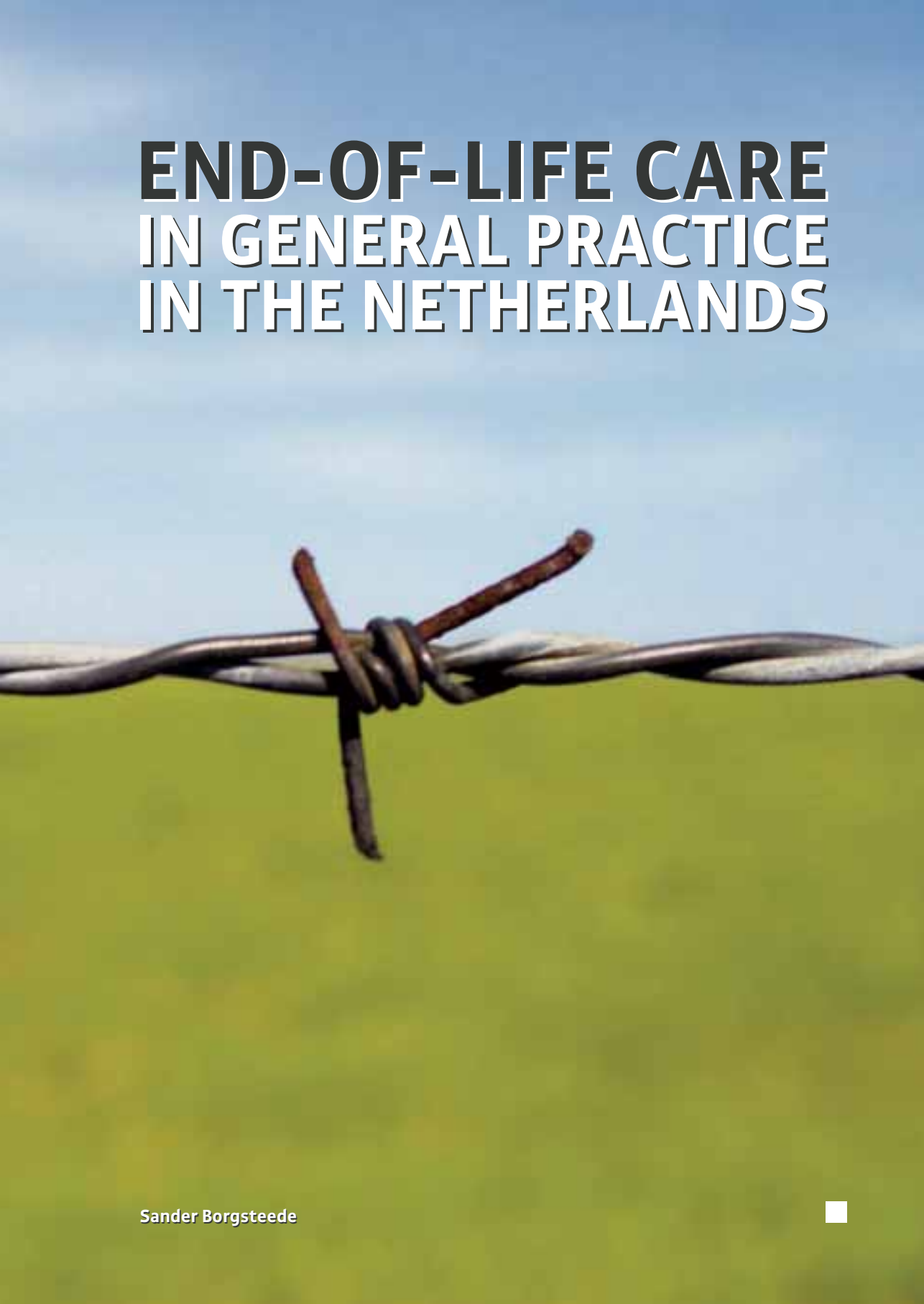
END-OF-LIFE CARE IN GENERAL PRACTICE IN THE NETHERLANDS



Sander Borgsteede

END-OF-LIFE CARE IN GENERAL PRACTICE IN THE NETHERLANDS

Sander Borgsteede

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END-OF-LIFE CARE IN GENERAL PRACTICE IN THE NETHERLANDS

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CONTENTS

CHAPTER 1

INTRODUCTION

End-of-life care in the Netherlands

Until the first decades of the 20th century, the main responsibility of doctors was care.[1] During the 20th century this attitude steadily changed, simultaneously with an epidemiological transition in Western societies that led to older populations and more patients with chronic diseases.[2] Determinants of the changes in demographics were improvements in public health (e.g. hygiene), cultural factors, socio-economical factors and new developments in medical care and technology.[3] Important was the use of antibiotics that made it possible to cure formerly lethal infections,[4] as were improvements in surgery, intensive care medicine and vaccination.[3] During this period of economic prosperity and interwoven changes in medicine, demographics and society, the goal of medical care gradually altered from care towards cure.[1]

By the 1950s, the main attitude in medicine was that cure was a possibility, and that medicine had failed when the doctor could not cure the patient.[5] Unfortunately, this optimism proved not to be a reality for all patients, and many died without being cured. These patients were often given a lower priority, and some died without attention to their pain and suffering in physical and psychosocial respects.[1] A response to these developments in the UK was the foundation of St. Christopher's Hospice in London, 1967.[6] Instead of the message that 'nothing could be done anymore', the hospice focused on pain and symptom control, nursing and psychosocial and spiritual care.[6] Other Western countries developed ways to deal with the needs of dying people as well.[7,8] Central in these developments was that there was something that could be done for patients who were not expected to recover, and that the complex and diverse symptoms of these patients needed a 'total care' approach.[1]

In the Netherlands, the development of end-of-life or so-called palliative care has been influenced by the strong emphasis on primary care.[9,10] Dutch general practitioners (GPs) have experienced care at home for dying patients as an important aspect of achieving their goal of 'integral, continuous and personal care' for dying patients.[11] From the time of the establishment of nursing homes in the 1960s, experience has been gained in the care of dying patients in this setting.[12] The first specialist palliative care service was developed in 1975, for terminally-ill patients in the nursing home 'Antonius IJsselmonde'.[9] In 1991, the first 'high care' hospice was founded: hospice Johannes in Vleuten.[7] Although there have always been concerns about appropriate end-of-life care, the focus of government policy on end-of-life care increased considerably during the 1990s.[13] The actual formal approach of the Dutch government is that palliative care should be provided as much as possible by generalists.[10,14,15]

To support initiatives concerning end-of-life care by generalists, the Minister of Health initiated a stimulation programme with the aim of providing palliative care preferably by doctors, nurses and care-workers in regular non-private settings.[13] The stimulation programme consisted of three specific separate programmes: (1) encouragement of research initiatives under a programme of the Health Research and Development Council/Medical Sciences (ZonMw); (2) promotion and guidance of palliative care by six university centres; the Centres for the Development of Palliative Care (COPZs); and (3) stimulation of the integration of hospice facilities in regular health care by the Hospice Care Integration Project Group (PIH). An important aspect of this policy was to make possible the responsible, complex and demanding tasks of providing palliative care, by stimulating adequate education, support and research for professional care providers working in primary care.

Professionalisation of end-of-life care at home in the Netherlands

Within primary care, the GP is the central professional in the management and coordination of the patient's treatment, and almost 100% of the inhabitants of the Netherlands have their own GP.[16] GPs also provide care to the inhabitants of the homes for the elderly. Almost 60% of the patients with non-acute illnesses die at home,[17] and there is a general consensus that end-of-life care preferably should be provided in the patient's home, if possible.[9] The ageing of the population and the growing number of non-acute deaths are expected to increase the GP's contribution to meeting the rising needs of terminally-ill patients.[18,19] These transitions in demographics, morbidity and mortality will require more effort from health care professionals, while the relative number of care givers decreases. GPs will work more frequently in primary care cooperatives and more GPs will work part-time.[20] These developments will change the goals and structure of primary care in the Netherlands. For these reasons, in the COPZ stimulation programme special attention was given to supporting the role of GPs with palliative care education programmes, professional support and academic research.

These initiatives to stimulate education involve both basic and postgraduate education. To integrate palliative care as a structural element in the basic academic training for medical doctors, courses were developed that were transferable to other academic settings.[21] The Dutch College of General Practitioners have set up and are running an intensive course on Palliative Care for General Practitioners.[21,22] This course is designed to train GPs as specialists in palliative care, and as consultants for colleagues.[23] Another structural educational programme is the Palliative Care Peer Group Training: an education based on inter-GP consultation.[24,25]

To support and enhance the expertise of primary care professionals, local palliative care consultant teams were developed. These teams are frequently consulted by GPs, and according to the requesting care givers, these consultations contributed to improving the quality of palliative care.[26] Since the discontinuation of the COPZs in 2002, consultation services for, among others, primary care have been continued by the Comprehensive Cancer Centres (IKCs).[27] This approach, in which the GP consults the palliative care consultation team, might help to enhance the general knowledge and experience of GPs in palliative care.[26]

End-of-life care research activities concerning general practice were initiated because few studies have been performed in order to describe and understand the role of the GP in palliative care. Pionering work was published in the thesis of Spreeuwenberg (1981) with his study of the role of the GP in caring for dying patients, using qualitative methods to explore how terminal care by the GP could influence the patient's quality of dying.[28] Other studies in general practice were performed by Schadé (1986) concerning cause of death and accompanying problems in treatment, care and guidance of end-of-life (cancer) patients[29], and by Van der Wal (1992), concerning end-of-life decision making.[30]

Recently, three research projects in palliative care have resulted in a PhD thesis on GP activities. In 1998, Schuit presented a thesis with studies that described several research and educational activities concerning palliative care for patients with cancer in general practice that had started in 1993.[31] He concluded that an active and patient-oriented approach was needed. Second, in 2001, Van den Muijsenbergh found that GPs were able to perform palliative care by such an approach, and that there were no great differences between the patient's expectations of palliative care and their needs according to the GPs.[32] She found that due to continuous personal relationships and integrated treatment of patient and family, the GP is able to perform palliative care. And third, in 2006, Osse successfully developed instruments with which the GP can assess the problems

and needs of cancer patients and their families in palliative care.[33]
Although these studies investigated important aspects of palliative care in general practice in the Netherlands, there are still significant gaps in knowledge. There are no studies that included non-cancer patients and we lack epidemiological data derived from large scale studies of representative populations. We also have no insight into the values of good care by patients and their GPs. To fill some of these gaps, two projects were started in the context of the COPZ-research programme: one in Nijmegen by Groot, and the other in Amsterdam, with the present thesis as a final result.

Aim and research questions
This thesis aims to investigate issues of current practice in end-of-life care in general practice in the Netherlands. The main aim is to study epidemiological issues of end-of-life care in general practice: we will investigate the needs of end-of-life patients, indicators for the quality of end-of-life care by the GP, and the organisation of end-of-life care at home. We also aim to explore the opinions of two important groups involved: the patients and their GPs.

A problem we encountered when we had to define inclusion criteria for the design of our study was that there is no generally accepted research definition of palliative care. This led us to our first research question:
- 1. What are the consequences of using different inclusion criteria on the selected palliative care populations in terms of size, number of doctor-patient contacts and demographic characteristics?

For the patient's needs we will focus on the prevalence of pain and symptoms in general practice. As indicator for the quality of palliative care, we will investigate the management of one of the most prevalent symptoms, pain, and compare the GPs' prescribing with current standards and guidelines. For the organization of care, we study cooperation between GPs and other care providers in palliative care. The accompanying research questions are:
- 2. What is the prevalence of pain and other symptoms in patients receiving palliative care at home?
- 3. What pain medication is prescribed to patients receiving palliative care at home?
- 4. What is the extent and the level of GP cooperation with other caregivers in palliative care at home?

We explore the opinions of the patients receiving end-of-life care and their GPs concerning two issues. First, we analyse their experiences with end-of-life care investigating what they consider as 'good care' by answering the next research question:
- 5. What are the aspects valued in end-of-life care at home by patients and their general practitioners?

As in the Dutch context euthanasia is one of the end-of-life options, our second exploration concerns communication about this topic. The final research question we will address is:
- 6. Do patients talk about euthanasia with their GP and if so, how do they communicate about this subject?

METHODS

Definitions and terms

So far in this introduction, we have alternately used the terms palliative care and end-of-life care. The most commonly used term is palliative care*, defined by the World Health Organization as: 'an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'.[34] However, for multiple reasons this definition is problematic, as we will explain in Chapter 2. The broadest approach denotes 'end-of-life' as the part of life when a person is impaired with an eventually fatal condition, even if the prognosis is ambiguous, e.g. patients with heart failure or chronic obstructive pulmonary disease (COPD).[35] We will refer to this meaning of 'end-of-life' when we talk about the care by the GP for patients who are provided with 'palliative care' or 'end-of-life care'. In this thesis, both terms have the same meaning, unless we directly refer to a particular definition.

Furthermore, we used the same terminology in this thesis as we used in our published and submitted articles. This implies that in the different chapters we use different words to indicate our setting: general practice for publications submitted to European journals and family practice for American journals. These terms both have the same meaning.

Data collection

For this thesis, data from two different studies were used. Quantitative data were collected within the framework of the Second Dutch National Survey of General Practice, and qualitative data were obtained by interviews with 30 patients and their GPs. This paragraph describes the main characteristics of these studies. In the various chapters the methods will be described in more detail.

The second Dutch National Survey of General Practice

In the second Dutch National Survey of General Practice (DNSGP-2) a representative sample of 104 Dutch family practices participated.[36] Data from eight practices were excluded: three practices delivered incomplete data; five practices were excluded because the data did not meet the minimum quality criteria. The study population of the remaining 96 practices was 375,899 patients. In these practices 2,194 patients died during the survey year (0.6%). The one-year period of each practice ended between April 2001 and January 2002. Computerised data for demographic characteristics, GP-patient contacts and prescribing were obtained.

At the end of the survey period, the GPs received a post-mortem questionnaire designed for this study for each patient who died during the survey year. In this questionnaire, the GPs reported the patient's underlying disease, answered questions on end-of-life care issues, and labelled each patient according to possible criteria for end-of-life care.

Patient and GP interviews

A total of 17 GPs who were following an advanced postgraduate training in end-of-life care, organized by the Dutch College of General Practitioners[22,37] and 14 of their colleagues

* PubMed Search 06-07-2006. Number of publications selected by "palliative care": free text=27,637, title words=3,515. Number of publications selected by "terminal care": free text=14,718, title words=691. Number of publications selected by "end-of-life care": free text=1,679, title words=686 (www.pubmed.gov).

without specific interest in end-of-life care, agreed to participate in qualitative interviews. Of the 31 participating GPs, 20 GPs included 30 patients who were receiving end-of-life care in their practices according to the following inclusion criteria: (1) a life expectancy of less than six months; (2) cancer, heart failure or chronic obstructive pulmonary disease as underlying disease; (3) the GP was (one of) the primary caregiver(s), and (4) the patient had adequate command of the Dutch language. Semi-structured, in-depth interviews were carried out in the patients' home. Approximately two weeks after the patient interview the GP was interviewed according to a similar topic list.

Outline of the thesis

Following this introduction, the chapters 2-7 of this thesis are based on articles, which have been published, accepted or submitted for publication. This implies that the various chapters overlap, especially with regard to the methods sections.

Chapter 2 describes the consequences of different definitions that may be used to include patients in palliative care populations: how do the populations differ from each other as the result of different inclusion criteria with regard to size, underlying disease, age distribution and gender?

Chapter 3 presents the symptoms that are prevalent in patients receiving palliative care in general practice in the Netherlands, and analyses differences between younger and older patients, males and females and cancer versus non-cancer patients.

In Chapter 4 we analyse the pharmacological management of pain: one of the most frequent and disturbing symptoms in palliative care. We investigate the prescribing of different drugs, the longitudinal development, and some aspects of the quality of prescribing.

Chapter 5 shows with whom Dutch GPs cooperate in the care of patients receiving end-of-life care at home. Potential predictors for cooperation between GPs and other caregivers will be analysed.

Chapter 6 explores the aspects valued in end-of-life care at home by patients and their GPs, and reflects upon these results in the context of future developments in European primary care.

In Chapter 7 we explore whether patients and their GPs talk about euthanasia and, if so, how they communicate about this subject, and discuss the meaning of communication about euthanasia in the context of end-of-life care.

Finally, in Chapter 8 we summarize the major findings and reflect on the methodological aspects of the studies. Also, we discuss the implications for the further development of end-of-life policy, practice, and research.

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CHAPTER 2

DEFINING THE PATIENT POPULATION: ONE OF THE PROBLEMS FOR PALLIATIVE CARE RESEARCH

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ABSTRACT

There is a lack of clear definition and clear inclusion criteria in palliative care research. The aim of this study was to describe consequences of three inclusion criteria in the build up of different study populations, studied in terms of size, number of doctor-patient contacts and demographic characteristics. General practitioners received a questionnaire for all patients who died during the second Dutch National Survey of General Practice (*n*=2,194), to determine whether (1) patients received non-curative treatment; (2) patients received palliative care; and (3) death was expected (total response rate = 73%). The criterion 'death was expected' included most patients (62%) followed by 'palliative care' (46%) and 'non-curative treatment' (39%). Similarity between the definition-based populations was fair to moderate. More 'palliative care' and 'death was expected' patients had cancer than 'non-curative treatment' patients. The conclusions show substantial differences in populations according to the different inclusion criteria used to select them. Future research in palliative care should acknowledge the limitations of using certain inclusion criteria and explore potential bias.

INTRODUCTION

In 1990, the World Health Organization (WHO) defined palliative care as 'the active total care of people whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social, emotional and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anticancer treatment'.[1] Nowadays, it is recognized that the principles of palliative care should be applied as early as possible in the course of any chronic disease. Hence, the WHO adapted the definition in 2002 to: 'an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'.[2] According to both WHO definitions palliative care 'intends neither to hasten nor postpone death'.[1,2]

Both definitions define the intentions or goals of palliative care, but are rather vague in describing the eligible population. While the goals are focusing on the symptoms and problems of the patients, the population in the WHO definitions is defined by the illness of the patient, ie, diseases not responsive to curative treatment (1990), or illnesses that are life-threatening (2002). As a consequence, palliative care populations have been defined by health policy makers or by researchers in many different ways.[3,4]A major problem in the further development of palliative care is the lack of an accepted way of defining research populations.[4-6] However, clear population criteria are essential to make possible the comparison of results across studies and countries.[5,6] In the study of a general population, the effects of the chosen inclusion criteria on the outcome and characteristics of the population are, as yet, unknown. Therefore, it is useful to know the effects of using different inclusion criteria on the build up of the selected populations.

The aim of this study was to discover and describe the consequences of using different inclusion criteria on the selected populations. We used three criteria. The first, treatment 'not directed at cure nor at life-prolongation', is taken directly from the 1990

WHO palliative care definition.[1] The second criterion, the treating physician labels the patient as 'were provided with palliative care', has been chosen because it is the most commonly used concept. Furthermore, this subjective label allows all kinds of factors which are related to palliative care in the perception of the labeler to be taken into account. Finally, the third criterion, the death of the patient was not 'suddenly and unexpectedly', was chosen to include patients who were at risk of receiving palliative care because their death did not occur unexpectedly. This criterion has been used in different Dutch and European end-of-life studies.[7,8]

The research question addressed in this study is: what are the similarities and differences in terms of size, number of doctor-patient contacts and demographic characteristics between the populations selected by the different criteria?

METHODS

Data collection

The data used in this study were obtained from the second Dutch National Survey of General Practice (DNSGP-2), in which a representative sample of 96 Dutch general practices participated with a total of 375,899 patients. The start of the one-year registration period in the study practices varied between April 2000 and January 2001.[9] In the participating general practices, approximately 1.6 million contacts with patients were digitally recorded, and in these files the morbidity and diagnoses were registered according to the International Classification of Primary Care (ICPC-1).[10] Data on the demographic and clinical characteristics of all patients were collected. The study was carried out according to Dutch legislation on privacy. The privacy regulation of the study was approved by the Dutch Data Protection Authority.[9]

Criteria for palliative care

In an additional questionnaire designed for this study, the patients who died during the period of registration were categorized according to the general practitioners' answers to three questions: (1) did this patient receive treatment directed at cure or life-prolongation? (2) did you or your co-operative provide palliative care? and (3) was the patient's death sudden and unexpected? We tried to make this text easier to read by translating these three questions into criteria, so that a 'yes' for a criterion meant that the patient received palliative care according to that criterion. We translated the questions as follows: if the general practitioner's answer to the first question was 'no, the treatment was not directed at cure nor at life-prolongation', we categorized the patient as positive on criterion 1: 'non-curative treatment'. A positive answer to question two, 'yes', implied inclusion on criterion 2: 'palliative care'. If the answer to question 3 was 'no', the patient was categorized positively on criterion 3: 'death was expected'. Figure 1 illustrates this categorization and shows the eight possible combinations, where combination 8 represents patients who were categorized as negative on all three criteria.

As all patients died during the year of registration, we had varying prior-to-death data. To analyse contact information, we defined a population of patients who died at least three months after the start of the study. In this population we analysed the contact registration with regard to the number of doctor-patient contacts over a fixed period of three months before death.

Analysis

To determine differences in the size of outcome populations, we used frequency tables.

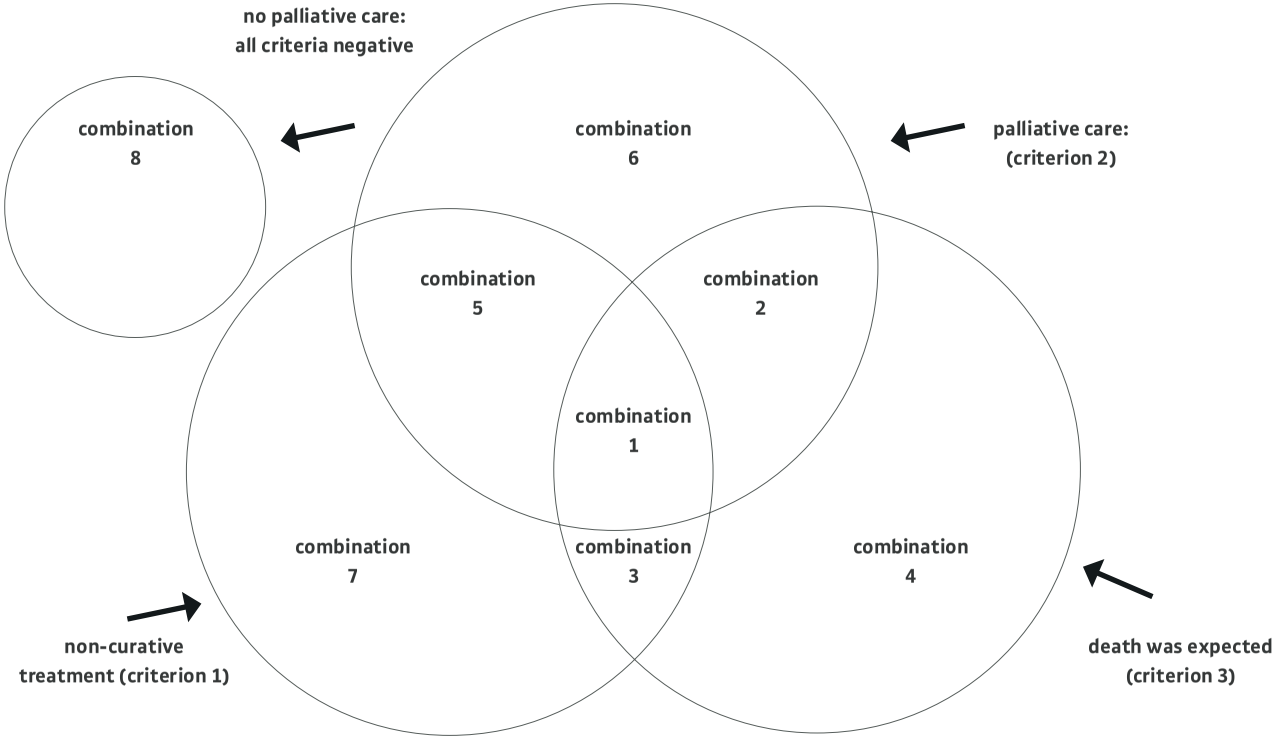

Figure 1.
Distribution of a palliative care population divided into 8 possible combinations of three criteria for palliative care: (1) non-curative treatment (1,3,5,7) , (2) palliative care (1,2,5,6) and (3) death was expected (1,2,3,4).

To answer the question about similarity, we compared the frequencies of the variables gender, age and underlying diseases within the three criteria, using frequency tables and kappas (κ) to express similarity: a value < 0.2 = poor similarity, between 0.21 and 0.40 = fair, 0.41 and 0.60 = moderate, 0.61 and 0.80 = good, and a value > 0.80 = very good similarity.[11] This comparison was carried out for the variable gender and underlying disease, using data from the complete sample. Data from fewer patients were available for comparing the number of doctor-patient contacts in the last three months of life, since some patients were excluded because they died within the first three months of the study. To answer the question on differences between populations of patients who met the inclusion criteria, a pair-wise comparison was made of the differences between the categories which excluded each other.

We used a χ-square test to determine whether of the differences were statistically significant, with an alpha-level of 5%. The same variables as for similarity were included in this analysis.

RESULTS

Population size

In the 96 general practices 2,194 of the 375,899 patients died during the year of registration (0.6%). Of the 2,194 questionnaires sent to the general practitioners, 1,771 were returned (81%), and 1,608 were filled in completely (73% valid response rate).
Most patients (69%) were categorized as positive on at least one palliative care criterion, and 26% on all three (Table 1). For 62% of all included patients death was expected, 46% received palliative care and 39% received non-curative treatment. In 31% of cases the patients did not fit any of the criteria.

Characteristics and similarities of included populations

There were no differences in the mean age and the gender proportions between the three criteria-based populations (Table 2). The similarity between the 'non-curative treatment' population versus both those defined as receiving 'palliative care' (κ=0.36) and 'death was expected' (κ=0.39) was fair; and between receiving 'palliative care' and 'death was expected' the similarity was moderate (κ=0.57).
In the 'non-curative treatment' population there were relatively fewer cancer patients and more patients with other diseases than in the other populations, and in the 'palliative care' population there were relatively more cancer patients than in the 'death was expected' population. For cancer as underlying disease similarity was poor between the 'non-curative treatment' population and the 'palliative care' and 'death was expected' populations, and fair between the 'palliative care' and 'death was expected' populations. Between all populations, similarity for heart failure as underlying disease was moderate, and for COPD it was poor to fair. The overall similarity between the three populations was fair to moderate.
A higher proportion of patients receiving 'palliative care' had at least one doctor-patient contact in the last three months of life (95%) compared to those receiving 'non-curative treatment' and those whose 'death was expected' (90%). The mean number of doctor-patient contacts was 12.4 for the 'palliative care' population, 11.2 for the 'non-curative treatment' population and 10.9 for the 'death was expected' population.

Table 1.
Size of palliative care population according to the three criteria studies: (1) non-curative treatment, (2) palliative care and (3) death was expected (*n*=1,608) .

No. of combination (see Figure 1)	Criterion 1: 'non-curative treatment'[a]	Criterion 2: 'palliative care' [b]	Criterion 3: 'death was expected'[c]	No.	%	
1	+	+	+	415	26	
2	-	+	+	264	16	
3	+	-	+	135	8	
4	-	-	+	177	11	69%
5	+	+	-	16	1	
6	-	+	-	48	3	
7	+	-	-	62	4	
8	-	-	-	491	31	
Total	628 (39%)	743 (46%)	991 (62%)	1,608	100	

[a] In the questionnaire we asked: 'did this patient receive treatment directed at cure or life-prolongation?' Criterion 1 was positive if the general practitioner answered 'no, the treatment was not directed at cure nor at life-prolongation'.

[b] In the questionnaire we asked: 'did you or your co-operative provide palliative care?' Criterion 2 was positive if the general practitioner answered this question with 'yes'.

[c] In the questionnaire we asked: 'was the patient's death sudden and unexpected?' Criterion 3 was positive if the general practitioner answered this question with 'no'.

Table 2.
Demographic characteristics, underlying diseases and number of contacts in a palliative care population and similarities (κ[a]) in variables between populations defined according to three criteria: (1) non-curative treatment (NCT), (2) palliative care (PC), and (3) death was expected (DE) (*n*=1,608)

	Criterion 1: NCT		Criterion 2: PC		Criterion 3: DE		1 versus 2	1 versus 3	2 versus 3
A: total population (*n*=1,608)	%		%		%		κ	κ	κ
Demographic characteristics									
Gender (male) (95% CI)	45	40-49	47	43-51	48	44-51	0.36	0.39	0.57
Mean age (SD)	79	13	75	15	76	14			
Underlying diseases									
Cancer	44	39-48	55	52-60	48	45-52	0.12	0.12	0.36
Heart failure	16	13-20	16	14-19	17	15-20	0.42	0.44	0.49
COPD	6.2	4.5-8.4	6.9	5.1-8.9	7.5	5.9-9.3	0.16	0.33	0.19
Other diseases	41	37-45	27	24-31	34	31-37	0.39	0.45	0.45
n total	628		743		991		0.36	0.39	0.54
B: complete data for the period three month before death (*n*=1,122)[b]	%		%		%		κ	κ	κ
Doctor-patient contacts									
At least one contact (95% CI)	90	87-93	95	93-98	90	87-92	0.37	0.37	0.55
Mean number of contacts (SD)	11.2	8.0	12.4	8.2	10.9	8.1			
n total	448		520		697				

[a] κ < 0.2 means poor similarity, 0.21-0.40 fair similarity, 0.41-0.60 moderate similarity, 0.61-0.80 good similarity and > 0.80 very good similarity.

[b] Only patients who died at least three months after the start of the study were included.

Characteristics and differences in populations excluded by the criteria

In Table 3 we focus pair-wise on the differences between populations excluded by each other. A total of 940 patients were defined by either 'non-curative treatment' or 'palliative care', and there was an overlap of 431 patients (combinations 1 and 5). Excluded by palliative care and only included by 'non-curative treatment' were 197 patients (combinations 3 and 7), compared to 312 patients included only by 'palliative care' (combinations 2 and 6). Between these two sub-populations, there was no difference in gender distribution, but patients exclusively categorized as 'non-curative treatment' were significantly older than patients exclusively categorized as 'palliative care'. The 'palliative care' population had a higher proportion of cancer patients and a lower proportion of patients with other diseases than the 'non-curative treatment' population. A higher proportion of patients exclusively categorized as 'palliative care' had at least one doctor-patient contact during the last three months of life, and the mean number of doctor-patient contacts in the last three months of life was higher, compared to the population exclusively categorized as 'non-curative treatment'.

Within the combination of 'non-curative treatment' and 'death was expected', there were 78 exclusive 'non-curative treatment' patients and 441 exclusive 'death was expected' patients. Between these two populations, there were no significant demographic differences, but the 'death was expected' population had a higher proportion of cancer patients and a lower proportion of patients with other diseases. No differences were found in the proportion of patients with at least one doctor-patient contact, but the mean number of doctor-patient contacts for 'death was expected' patients was higher than for 'non-curative treatment' patients.

Within the combination of 'palliative care' and/or 'death was expected', there were 64 exclusive 'palliative care' patients and 312 exclusive 'death was expected' patients. Between these two sub-populations there was no difference with regard to gender, age and underlying disease. Compared to the 'death was expected' patients, more 'palliative care' patients had at least one doctor-patient contact, and the mean number of doctor-patient contacts for these patients was higher.

DISCUSSION

In this study, we applied three different criteria for palliative care to the same palliative care research population, namely (1) non-curative treatment, (2) palliative care or (3) death was expected. This made it possible to compare similarities and differences between the selected sub-populations. The criterion 'death was expected' included most patients (62%) followed by 'palliative care' (46%) and 'non-curative treatment'(39%). Similarity between the three definition-based populations was fair to moderate. More 'palliative care' and 'death was expected' patients had cancer than 'non-curative treatment' patients, and the 'palliative care' population had more doctor-patient contacts.

This study was embedded in the second Dutch National Survey of General Practice (DNSGP-2), a nationwide study of doctor-patient contacts in a representative sample of general practices in the Netherlands.[9] With mean non-response rates of 39% reported in published studies carried out in general practice, and a trend of decreasing rates of response to mail questionnaires, the total response rate of 73% for the additional questionnaire was high.[12] However, this study has some limitations. The DNSGP-2 was not designed specifically for palliative care research, so there was no data available on several items that are relevant for palliative care. For example, there is no data available

Table 3.
Demographic characteristics, underlying diseases and number of contacts of palliative care patients excluded by three criteria: (1) non-curative treatment (NCT), (2) palliative care (PC), and (3) death was expected (DE) and differencesa in variables between sub-populations (*n*=1,608).

	Criterion 1 versus criterion 2			Criterion 1 versus criterion 3			Criterion 2 versus criterion 3		
	(NCT)	(PC)		(NCT)	(DE)		(PC)	(DE)	
	%	%	P	%	%	P	%	%	P
A: total population (*n*=1,608)	628	743		628	991		743	991	
Overlap	431	431		550	550		679	679	
	(69%)	(58%)		(88%)	(55%)		(91%)	(69%)	
Excluded	**197**	**312**		**78**	**441**		**64**	**312**	
	(31%)	**(42%)**		**(12%)**	**(45%)**		**(8.6%)**	**(31%)**	
Demographic characteristics									
Gender (male)	47	52	n.s.	45	51	n.s.	48	48	n.s.
Mean age	79	72	<0.001	78	74	n.s.	79	79	n.s.
Underlying diseases									
Cancer	21	58	<0.001	10	48	<0.001	17	24	n.s.
Heart failure	18	18	n.s.	18	20	n.s.	33	24	n.s.
COPD	8	9	n.s.	2,6	8.4	n.s.	16	11	n.s.
Other diseases	60	22	<0.001	69	30	<0.001	42	51	n.s.
B: complete data 3 months before death (*n*=1,122)[b]	448	520		448	697		520	697	
Overlap	314	314		393	393		477	477	
	(70%)	(60%)		(88%)	(56%)		(92%)	(68%)	
Excluded	**134**	**208**		**55**	**304**		**43**	**220**	
	(30%)	**(40%)**		**(12%)**	**(44%)**		**(8.3%)**	**(32%)**	
Doctor-patient contacts									
At least one contact	78	96	<0.01	85	89	n.s.	95	78	<0.01
Mean number of contacts (SD)	6.1 (4.7)	11 (8.3)	<0.001	5.5 (4.0)	9.6 (7.9)	<0.01	8.1 (5.8)	6.0 (4.7)	<0.05

[a] Differences between sub-populations were calculated with a χ-square-test. For means (age) we used a Student's *t*-test.
[b] Only patients who died at least three months after the start of the study were included.

on some important and relevant issues that might have influenced the need for palliative care and the number of doctor-patient contacts, e.g. whether or not the patients had a reliable support system.[13]

The findings of this study have implications for the understanding of the composition of populations included in palliative care research. First, the overall distribution shows that there is little similarity between patient groups defined as 'end-of-life' patients. It also illustrates the extreme difficulty of defining groups in palliative care research. One explanation for this might be that the three pragmatically chosen criteria measure related, but somewhat different concepts. 'Non-curative treatment' might measure the intention of palliative treatment, and the second criterion 'palliative care' might measure whether the general practitioner considers the care to be palliative. This may be linked to the severity of the problems and the frequency of doctor-patient contacts. The third criterion 'death was expected' might measure the likelihood that the patient would die soon. Hence, these three concepts are not fully interchangeable, and do not generate populations with a full overlap. Apparently, patients receiving palliative care can, at the same time, be receiving non-curative treatment, and their death is not always expected.

Furthermore, the labeling of patients may possibly influence patient care itself. In a study focusing on patients with colon and lung cancer, patients whose general practitioner considered the care to be palliative, died earlier than those who whose general practitioner did not.[14] This might indicate that the label 'palliative care' is associated with a more serious illness. Our study shows that the 'palliative care' population included patients who had more doctor-patient contacts than patients included by the other criteria, and that most of these patients had cancer. This supports the argument that palliative care is related to intensified care. However, the question is: do these patients receive the label 'palliative care' because they have cancer, or because they need and receive intensified care? If it is the first reason, patients with a chronic illness who are labeled as 'death was expected', but not as 'palliative care' patients, might possibly be excluded from receiving the more intensified care that they might need.

Given the major research consequences of applying different inclusion criteria, we still face the problem of choosing the best criterion for palliative care research. This study shows that there are substantial differences between populations when certain criteria are chosen. Future research should focus on further investigation of the diversity in characteristics of palliative care populations. This is only possible if future studies describe in more detail the way in which their population is included.

If we want to describe differences between sub-populations without omitting any potential palliative care patients, we must apply the broadest possible inclusion criteria. Hence, we recommend the use of a combination of different inclusion criteria, which should include at least 'palliative care' as labeled by (professional) carers, the intention of the palliative care treatment provided, and an assessment of the patient's life-expectancy, not meant to predict because this is rather difficult,[15] but as an indicator of the possibility of a palliative care trajectory.

To improve our current knowledge about palliative care, it would be preferable if we could find an internationally accepted combination of criteria to make it possible to compare palliative care in different settings, countries and sub-populations. This can be the starting point for the development of an internationally accepted research definition, something that is essential for the further development of palliative care research.

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CHAPTER 3

SYMPTOMS IN PATIENTS RECEIVING PALLIATIVE CARE: A STUDY ON PATIENT-PHYSICIAN ENCOUNTERS IN FAMILY PRACTICE

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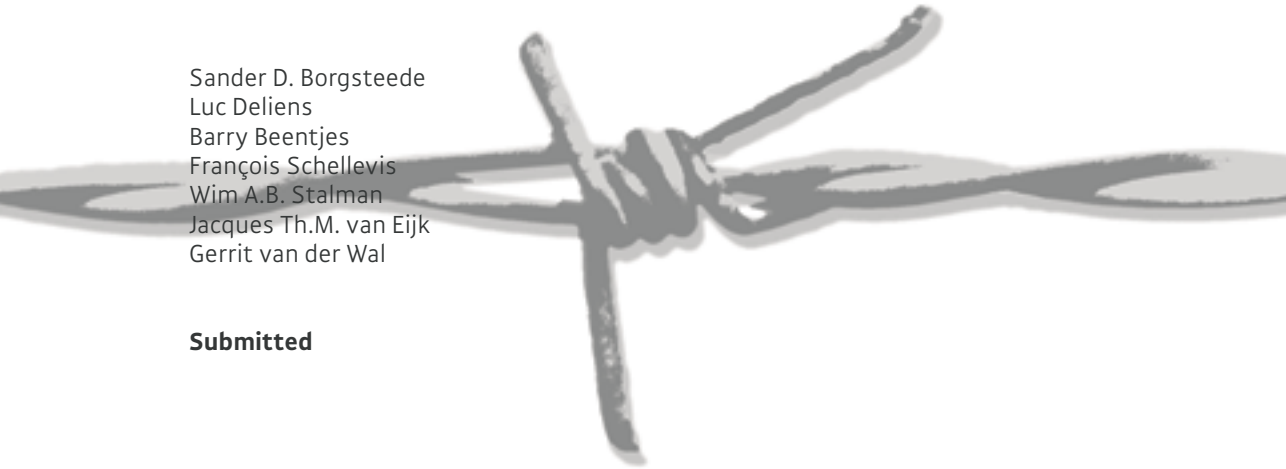

Submitted

ABSTRACT

Most people with an incurable disease prefer to stay and die at home, cared for by their family physician. This study aims at describing the prevalence and frequency of symptoms in patients receiving palliative care at home. Within the framework of a nation wide survey of family practice in the Netherlands, family physicians identified those patients who received palliative care out of all patients who died within the one-year survey period (valid response rate 73%). Patients with an observation period of at least three months, and who received palliative care by their family physician until death were included (*n*=429). Information regarding encounters during the last three months of life was derived from the electronic medical records kept by the family physicians. A symptom was prevalent when it was registered by the family physician in a patient-physician encounter. Digestive symptoms (59%) and pain (56%) were the most prevalent. The mean number of symptoms was higher in cancer patients (11.99) than in non-cancer patients (7.62). The number of digestive symptoms, pain and psychological symptoms was higher in the lower than in the higher age groups, and higher in cancer than in non-cancer patients. Most symptoms (36%) were concentrated in the last two weeks of life. Not reported in previous palliative care studies were musculoskeletal symptoms (20%), chronic ulcer (18%) and discussion about euthanasia (14%). Future studies should explore the severity and influence on quality of life of these lesser known symptoms in palliative care.

INTRODUCTION

Most people with an incurable disease prefer to remain at home surrounded by relatives during the last stage of their life.[1-3] In the Netherlands, health care is characterised by its strong emphasis on primary care, where the family physician is the central professional in the management and coordination of the patient's care.[4] Almost 60% of the patients with non-acute illnesses die at home,[5] and there is a general consensus that palliative care preferably should be provided in the patient's home.[6] The aging of the population and the growing number of non-acute deaths will increase the need for palliative care.[7,8] This will also impact on the family physician's workload.

Symptom management is an important aspect of palliative care, as the World Health Organization (WHO) defines palliative care as: 'an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'.[9] Common symptoms in palliative care are pain, dyspnoea, constipation, confusion, nausea and vomiting.[10,11] Most studies on symptoms were performed in a specific setting, such as a palliative care unit in a hospital or a hospice. Findings from these specialised settings are not always transposable to the community as symptom prevalence differs between settings.[12] To our knowledge, there is no study in primary care that measures symptoms in a general population receiving palliative care.

Several patient characteristics are associated with symptom prevalence. The underlying disease seems to influence prevalence of symptoms e.g. in patients with heart failure who died in a hospice the symptom profile was different from cancer patients.[13] In cancer patients, symptom prevalence was found to differ with severity of the disease, gender and age.[14] However, primary care studies have not yet reported on both cancer

and non-cancer patients within the same study.
Family physicians face symptoms in palliative care patients during patient-physician encounters. Detailed information on the prevalence and frequency of symptoms in primary care is scarce and fragmented. However, this information is needed to organise future palliative care, to focus education on the most frequent symptoms and to initiate collaboration between relevant disciplines. This study aims to fill this gap by describing the prevalence and frequency of symptoms in patients receiving palliative care at home and to analyse differences by gender, age and underlying disease; i.e. in cancer and non-cancer patients. Furthermore, we aim to longitudinally investigate the prevalences of symptoms in six two-week periods until death.

METHODS

Patients

The data used in this study were obtained from the second Dutch National Survey of General Practice (DNSGP-2), in which a representative sample of 104 Dutch family practices participated, with a total of 399,068 patients involved.[15] Data from eight practices were excluded; three practices delivered incomplete data; five practices were excluded because the data did not meet the minimum quality criteria. The listed population of the remaining 96 practices was 375,899 patients. In these practices 2,194 patients died during the survey year (0.6%). The one-year period of each practice ended between April 2001 and January 2002.
At the end of the survey period, the family physicians received a post-mortem questionnaire designed for this study for each patient who died during the survey year. They reported the patient's underlying disease, and labeled each patient who received palliative care patient by indicating whether the patient was or was not *'provided with palliative care until death'*. Of the questionnaires sent to family physicians, 1,771 were returned (81%), and 1,608 were filled in completely (73% valid response rate).
As deaths occured throughout the survey year, we had a varying follow-up: some patients died in the first days of the survey, others died later in the study. To ensure we had an observation period of at least three months for each patient, we defined our source population as those who died at least three months after the start of the survey year (n=1,115). We defined our study population as patients with an observation period of at least three months, and who were labeled as palliative care patients by their family physician (n=429; 38%).

Measurements

- *Symptoms:* the family physicians defined the patient's health problem according to the ICPC.[16] This could be either a symptom or a disease diagnosis. In addition, the digital free text information about the contact registered by the family physicians was available. To retrieve as much information as possible, all free text information was read and scored using a restrictive list of symptoms, combining information from previous studies.[12,14,17-21] A symptom was present when it was registered by the family physician either as ICPC code, or as free text. The scoring of free text was subject to inter-rater reliability testing. Cohen's kappas were calculated and the inter-rater reliability was good (κ=0.79).[22]

Symptoms were classified in main categories according to the ICPC chapters based on body systems, in combination with general symptoms, pain and fatigue. Symptoms in body systems with a prevalence larger than 20% were named according to the specific ICPC-chapter, all other were lumped in the category 'other'. Within this classification we made sub categories of symptoms with a prevalence larger than 5%, all other were categorised as 'other symptoms' under the relevant body system.

- *Frequency:* data based on routine care delivery during the one-year study period were extracted from the electronic patient records. For all patients, encounters were analysed during the three months before the patient's death. The frequency of symptoms was expressed as the number of days on which the specific symptom was registered during a patient-physician encounter. Means for number of symptoms were calculated for the total population, and for the patients who had at least one encounter concerning the specific symptom.

- *Prevalence:* the prevalence of a symptom was defined as the number of patients with at least one encounter about a specific symptom during the last three months of life (numerator) divided by the total number of patients (denominator).

Furthermore, patient characteristics were extracted from the patient registration data of the practice administration. In the post-mortem questionnaire, we asked about existing underlying diseases using a limitative list.

Statistical analysis

Characteristics of the palliative care population were analysed. Descriptive statistics were used for prevalence of symptoms in palliative care patients and the mean number of symptoms per patient. Differences in prevalence of symptoms between sub-populations were calculated for the characteristics sex, age and underlying disease, i.e. cancer versus non-cancer patients, and tested using χ-square test (α= 0.05). The mean number of symptoms was compared between sexes and between cancer and non-cancer patients with Student's *t*-tests. For the longitudinal analysis during the last 12 weeks of life, we calculated the prevalence of symptoms in six two-week periods before the patient's death.

RESULTS

Prevalence and frequency of symptoms

In total, 429 patients with an observation period of at least three months received palliative care by their family physician until death. Characteristics of the study population are presented in Table 1. In patient-physician encounters during the last three months of life, the mean number of symptoms registered by the family physician was 10.0 (Table 2). Digestive symptoms were prevalent in 255 (59%) of the patients. The total number of digestive symptoms was 887, resulting in a mean number of 2.07 per patient in the last three months of life. Within the digestive symptoms, most patients had problems with eating or drinking (29%), and nausea or vomiting (25%). The prevalence of pain in palliative care patients was 56%. Within psychological symptoms, restlessness (25%), sleeping problems (17%) and anxiety (13%) were the most prevalent symptoms. Within the category other, musculoskeletal symptoms (20%), chronic ulcer (18%) and requests for/talking about euthanasia (14%) were most common. There was a mean number of

Table 1.
Characteristics of the study population of patients who received palliative care until death in family practice in the Netherlands, with an observation period of at least three months (*n*=429).

	% (*n*=429)
Sex	
Male	47
Female	53
Age (years)	
< 70	28
70-79	24
80-89	31
≥ 90	16
Mean (SD)	76.8 (13.9)
Underlying disease*	
Cancer	56
Non-cancer	44
Heart failure	11
COPD	3.1
Other disease	25
Multiple non-cancer diseases	4.5

* Number of missing values for underlying disease was 3.

Table 2.
Prevalence and frequency of symptoms in patients receiving palliative care during the last three months of life (*n*=429).

Symptom	Prevalence % (*n*)	Number of symptoms	Mean number of of symptoms (all patients)
Digestive	**59 (255)**	**887**	**2.07**
Problems with eating or drinking	29 (124)	208	0.48
Nausea or vomiting	25 (107)	253	0.59
Constipation	19 (81)	113	0.26
Diarrea	9.3 (40)	70	0.16
Anorexia	8.6 (37)	59	0.14
Mouth problems	6.5 (28)	29	0.07
Other digestive symptoms	20 (87)	155	0.36
Pain	**56 (240)**	**801**	**1.87**
Psychological	**45 (194)**	**517**	**1.21**
Restlessness /confusion	25 (107)	214	0.50
Sleeping problems	17 (74)	113	0.26
Anxiety	13 (55)	75	0.17
Depression	8.6 (37)	49	0.11
Other psychological symptoms	11 (47)	66	0.15
Respiratory	**44 (189)**	**587**	**1.37**
Dyspnoea	27 (115)	287	0.67
Coughing or slime	20 (84)	146	0.34
Infection	16 (67)	109	0.25
Other respiratory symptoms	7.5 (32)	45	0.10
Fatigue	**36 (153)**	**327**	**0.76**
Urogenital	**31 (131)**	**235**	**0.55**
Circulatory	**24 (104)**	**180**	**0.42**
Oedema	16 (69)	95	0.22
Anaemia	8.9 (38)	71	0.17
Other circulatory symptoms	2.1 (9)	14	0.03
Other	**63 (272)**	**775**	**1.81**
Musculoskeletal symptoms	20 (85)	167	0.39
Chronic ulcer	18 (77)	162	0.38
Request for/talking about euthanasia	14 (58)	123	0.29
Feeling ill	5.8 (25)	53	0.12
Itching	5.8 (25)	33	0.08
Dizziness	5.6(24)	30	0.07
Other	30 (129)	207	0.48
Total	**98 (419)**	**4309**	**10.0**

10.0 symptoms in the last three months of life, and the corresponding range was wide (0-68, median=8).

Symptoms by sex, age and underlying disease

There was no difference in the prevalence of symptoms between males and females receiving palliative care at home. The mean number of respiratory symptoms and fatigue was higher in males than in females, while the mean number of other symptoms was higher in females ($p < 0.05$, data not shown).

There was a lower prevalence of digestive symptoms, pain and psychological symptoms by patients in older age groups (Table 3). The prevalence of urogenital symptoms was higher in older age groups. The mean number of symptoms was significantly higher in patients younger than 70 years (11.25) than in patients older than 90 years (9.0).

Cancer patients had more pain, digestive symptoms, psychological symptoms and fatigue than non-cancer patients (Table 4). Compared to cancer patients, non-cancer patients had more urogenital symptoms. The mean number of all symptoms was 12.99 for cancer patients and 7.62 for non-cancer patients.

Table 5 shows symptom prevalences for cancer and non-cancer patients by age-group. In cancer patients, the prevalence of psychological symptoms was lower in older age-groups. This trend was not significant for pain. In cancer patients, prevalence of fatigue and urogenital symptoms was higher in older age-groups. In non-cancer patients the prevalence of fatigue and other symptoms was higher in older age-groups.

Symptoms during the last 12 weeks of life

Figure 1 shows the prevalence of symptoms in different body systems in the last three months of life. With the exception of circulatory and urogenital symptoms, all symptoms showed a small increase in prevalence in the period 2-3 weeks before death and a substantial increase in prevalence in the last two weeks before death. In total, 36% of all symptoms within the three month period occurred in the last two weeks of life and 61% of all patients had at least one symptom during these last two weeks.

DISCUSSION

In the patients who died at home and who received care until death by their family physician, digestive symptoms (59%), pain (56%) and psychosocial symptoms (45%) were most prevalent. Also, musculoskeletal symptoms (20%), chronic ulcer (18%) and request for/talking about euthanasia (14%) were prevalent in patient-physician encounters. The mean number of encounters about any symptom was higher in cancer patients (11.99) than in non-cancer patients (7.62). Also, in younger patients and in cancer patients the prevalence of digestive symptoms, pain and psychological symptoms was higher than in the elderly. Most symptoms (36%) were concentrated in the last two weeks of life.

This study was embedded in the second Dutch National Survey of General Practice, which has generated solid data due to its quality and size. The total response rate of 73% for the additional questionnaire was high compared to mean response rates of 61% reported in studies carried out in general practice, and a trend of decreasing rates of response to mail questionnaires.[23] As most studies in palliative care are limited to cancer patients[24], a further strength is that this study is population based, and that we included both cancer and non-cancer patients.

Table 3.
Prevalence and the mean number of symptoms in patients receiving palliative care during the last three months of life by age (*n*=429).

	< 70 years		70-79 years		80-89 years		≥ 90 years		
	Prevalence (%)	Mean number of symptoms	Prevalence (%)	Mean number of symptoms	Prevalence (%)	Mean number of symptoms	Prevalence (%)	Mean number of symptoms	*p* (χ-square)[a]
Digestive	67	2.78	66	2.02	52	1.49	51	2.04	0.006
Pain	66	2.26	62	2.22	49	1.60	44	1.19	0.000
Psychological	58	1.41	47	1.26	38	1.07	34	1.04	0.000
Respiratory	47	1.71	47	1.46	39	1.15	46	1.09	0.478
Fatigue	36	0.77	36	0.90	35	0.71	36	0.66	0.952
Urogenital	20	0.36	30	0.46	36	0.73	39	0.66	0.002
Circulatory	21	0.33	31	0.52	23	0.41	23	0.42	0.985
Other	62	1.64	60	1.70	65	1.99	67	1.90	0.339
Total	94	11.25	94	10.54	90	9.14	94	9.00	0.424

[a] χ-square for trend. Lineair-by-linear association

Table 4.
Prevalence and the mean number of symptoms in patients receiving palliative care during the last three months of life: cancer versus non-cancer patients (*n*=426).

	Cancer		Non-cancer			
	Prevalence (%)	Mean number of symptoms	Prevalence (%)	Mean number of symptoms	*p* (χ-square)	*p* (Student's-*t*)
Digestive	72	2.75	43	1.19	0.000	0.000
Pain	65	2.62	45	0.93	0.000	0.000
Psychological	53	1.45	36	0.91	0.000	0.005
Respiratory	42	1.48	45	1.22	0.623	0.268
Fatigue	45	1.00	24	0.46	0.000	0.000
Urogenital	25	0.44	37	0.69	0.008	0.017
Circulatory	25	0.42	23	0.41	0.820	0.872
Other	64	1.82	63	1.80	0.840	0.959
Total (at least one)	94	11.99	91	7.62	0.454	0.000

Table 5.
Prevalence of symptoms in patients receiving palliative care during the last three months of life, by age and underlying disease (*n*=426).

	< 70 years	*n*=120	70-79 years	*n*=102	80-89 years	*n*=135	≥ 90 years	*n*=69	Cancer	Non-cancer
	Cancer (%)	Non-cancer (%)	Cancer (%)	Non-cancer (%)	Cancer (%)	Non-cancer (%)	Cancer (%)	Non-cancer (%)	*p*[a] (χ-square)	*p* (χ-square)
Digestive	69	46	77	44	73	41	77	45	0.409	1.000
Pain	67	55	68	50	58	44	54	43	0.222	0.387
Psychological	61	36	54	32	40	38	39	34	0.010	1.000
Respiratory	47	46	46	47	29	44	39	46	0.086	1.000
Fatigue	39	9	47	15	52	25	62	30	0.038	0.043
Urogenital	19	27	28	35	29	39	46	37	0.026	0.593
Circulatory	21	18	31	29	23	23	31	21	0.449	0.684
Other	64	36	63	53	65	66	62	70	0.925	0.021
n	109	11	68	34	48	87	13	56		
	(91%)	(9%)	(67%)	(33%)	(36%)	(64%)	(19%)	(81%)		

[a] χ-square for trend. Lineair-by-linear association.

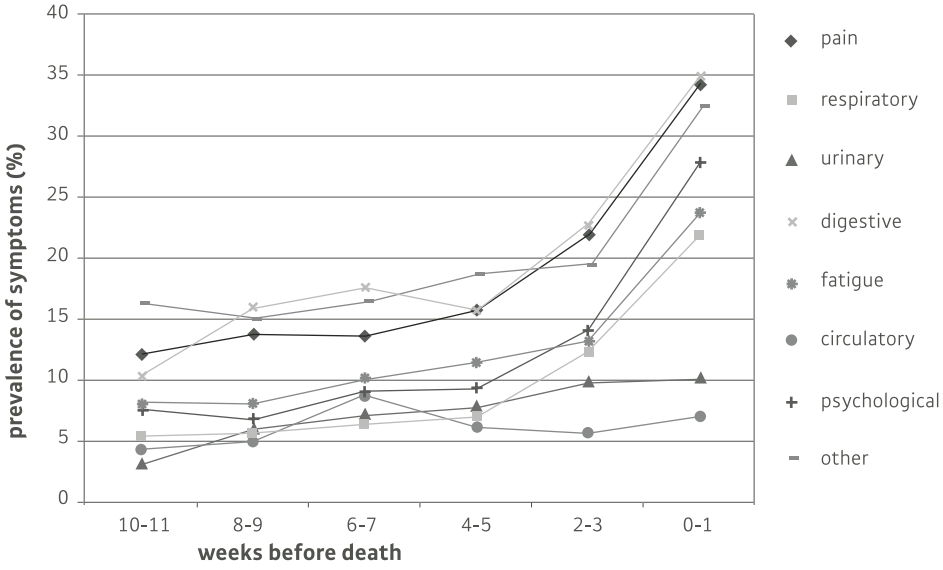

Figure 1.
Prevalence of symptoms in patients receiving palliative care in six two-week periods before death.

The limitations of this study are that no information was obtained about the severity of symptoms, and we were unable to measure whether the management of the symptoms resulted in improvement of symptom control. Besides, we measured symptoms that were prevalent in encounters according to physicians. In primary care, agreement between patients and family physicians assessment on the prevalence of physical symptoms is acceptable,[17] but it is likely that family physicians did not register all symptoms affecting these patients. Hence, it is likely that patients had other symptoms that did not result in a registration or in a patient-physician encounter, and that the numbers of symptom related encounters we found are underestimations of total symptom prevalence in patients receiving palliative care at home. Nevertheless we may presume that the symptoms registered in the electronic medical records represent the most important symptoms for both the patient and the family physician.
The most important result is that prevalence of symptoms differs by age group and underlying disease. Overall, prevalence of symptoms is higher for younger patients and for cancer patients. For cancer patients, prevalence of pain and psychological problems decreases with age, while prevalence of fatigue and urogenital symptoms increases with age. Because of the different nature of the disease, the frequency of symptoms in cancer patients might be higher than in non-cancer patients. On the other hand, a study that compared symptoms in lung cancer patients with COPD patients, found a similar symptom burden in both patient populations.[25] As we have not measured the needs, the severity of symptoms and the need for encounters we cannot say whether the received care met the needs of the patients.
Other studies have found that prevalence of symptoms was higher in younger patients.[14,26] Our study confirms this general finding in both cancer and non-cancer patients, although

some symptoms show a higher prevalence in older age groups e.g. fatigue and urogenital symptoms. A possible explanation for the finding that younger patients and cancer patients have more encounters about symptoms is that they can stay at home with a more severe disease because they have a reliable support system or that older patients have a more mitigated disease trajectory.[27]

The wide range of symptom prevalence across studies, and between patients within a study, makes comparisons between studies difficult. Our study is based on symptoms registered during encounters, where most other studies measured symptoms that were prevalent using a list of possible symptoms, e.g. the Palliative care Outcome Scale (POS) or the Edmonton Symptom Assessment System (ESAS).[28,29] Hence, symptom prevalence is probably underreported in our study.

Not reported in previous palliative care studies were musculoskeletal symptoms, chronic ulcer and request for/talking about euthanasia. The first two might be included in future palliative care studies on symptom prevalence. The last seems to be a typically Dutch subject as communication on euthanasia is part of communication on end-of-life preferences in the Netherlands.[30] Future studies should explicitly explore the prevalence of, and the need for communication on end-of-life issues in patients receiving palliative care.

This study shows that the number symptoms is the highest for cancer patients and that it is concentrated in the last two weeks of life. This requires a peak performance from family physicians, especially when they care for more than one palliative care patient at a time. In primary care, future developments such as the restriction of time for home visits, more part-time jobs and cooperatives responsible for care after office hours[4], may threaten the core values of palliative care, such as the availability of the family physician for home and after-hours visits.[31] Palliative care faces the challenge of combining these future developments with the necessity for family physicians to be available to give palliative care to more patients needing symptom control.

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PRESCRIBING OF PAIN MEDICATION IN PALLIATIVE CARE: A SURVEY IN FAMILY PRACTICE

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ABSTRACT

This study aims to understand what pain medication is prescribed to patients receiving palliative care at home, and to determine the longitudinal development of prescribing during the last three months of life. We also examine whether family physicians prescribe analgesics according to the WHO analgesic ladder, and if opioids are combined with laxatives. Within the framework of a nation-wide survey of family practice in The Netherlands, family physicians identified from amongst all patients who died within the one-year survey period those who received palliative care (response-rate 74%). We analysed the prescribing data of analgesics, laxatives and antiemetics to patients with an observation period of at least three months (*n*=425). Of these patients, 73% were prescribed pain medication: 55% a drug from step 1 of the WHO analgesic ladder (acetaminophen, NSAIDs), 21% a step 2 drug (weak opioids), and 51% a step 3 drug (strong opioids). More younger patients were prescribed a strong opioid, and more cancer patients were prescribed a drug from all three steps of the WHO analgesic ladder. The proportion of patients prescribed a step 1 or 2 drug increased gradually, and the proportion of patients prescribed a step 3 drug increased exponentially nearing the patient's death. In 40% of patients prescribed a step 1 analgesic, prescription of a strong opioid was not in line with the WHO analgesic ladder. A total of 48% was prescribed an opioid without any prescribed laxative. Current practice concerning the use of the WHO analgesic ladder and the prescribing of laxatives differs substantially from accepted guidelines.

INTRODUCTION

Most people with an incurable disease prefer to remain at home surrounded by their relatives during the last part of their lives.[1-3] In the Netherlands, health care is characterised by its strong emphasis on primary care, where the family doctor is the central professional in the management and coordination of the patient's treatment.[4] Almost 60% of patients with non-acute illnesses die at home,[5] and there is a general consensus that palliative care should be provided in the patient's home if possible.[6] The aging population and the growing number of non-acute deaths are expected to increase the family physician's contribution to meeting the increasing needs of terminally-ill patients.[7,8]

Pain is one of the symptoms that physicians most frequently encounter in patients receiving palliative care.[9,10] An important aid for pain management that was developed as an educational tool for the treatment of cancer pain, is the World Health Organization (WHO) analgesic ladder. According to the WHO analgesic ladder, pain management is a part of comprehensive palliative care which includes psychosocial and spiritual care. Drug treatment is the mainstay of cancer pain management and is composed of three steps of pharmacological therapy.[11,12] The sequential use of drugs starts with the non-opioid analgesics acetaminophen and nonsteroidal anti-inflammatory drugs (NSAIDs) in step 1, as well as adjuvant drugs to treat adverse effects, to enhance pain relief or to treat concomitant psychological disturbances.[11] Opioids for mild to moderate pain are prescribed in step 2 and opioids for moderate to severe pain in step 3. Non-opioid analgesics and adjuvant drugs from step 1 may be combined with step 2 and step 3 opioids. Pain management according to the WHO guideline is effective,[13] yet substantial improvement in the control of pain is still possible: pain management by clinicians and

in the community is suboptimal,[14-16] and patients lack adherence with their analgesic regimen.[17] Above, although recommendations state that opioids should be combined with laxatives to prevent obstipation, and might be combined with antiemetics to prevent nausea, still many doctors prescribe opioids without prescribing a laxative simultaneously.[18-20]

Data about the treatment of pain and the prescribing of pain medication are often derived from specialised settings,[21,22] and these are not always transposable to the community as the prevalence and treatment of pain differs between settings.[9] To our knowledge, there is no study in primary care that has measured the prescribing of pain medication in a general population receiving palliative care at home from their family physicians. To indicate whether there is a potential problem in a general population and, if so, to predict the magnitude of this problem, population-based statistics are needed. Above all, statistics showing the current prescribing patterns can serve as a reference point with which to compare future studies or studies in different countries, and as a source of information to guide the future education of patients and prescribers.

To understand better what drugs are prescribed, and to determine the longitudinal development of prescribing during the last three months of life, we aimed firstly to investigate the prescribing of pain medication in patients receiving palliative care in family practice, and to analyse differences by gender, age and underlying disease; i.e. in cancer and non-cancer patients. Secondly, we examined two aspects of the quality of prescribing: (1) whether family physicians prescribed analgesics according to the WHO analgesic ladder, and (2) if opioids were combined with laxatives and antiemetics.

METHODS

Patient selection

The data used in this study were obtained from the second Dutch National Survey of General Practice (DNSGP-2), in which a representative sample of 104 Dutch family practices participated, with a total of 399,068 patients involved.[23] Data from nine practices were excluded; four practices delivered incomplete data; five practices were excluded because the data did not meet the minimum quality criteria. The listed population of the remaining 95 practices was 374,070 patients. In these practices 2,169 patients died during the survey year (0.6%). The one-year period of each practice ended between April 2001 and January 2002.

At the end of the survey period, the family physicians received a post-mortem questionnaire designed for this study for each patient who died during the survey year. They reported the patient's underlying disease, and labeled each patient who received palliative care by indicating whether the patient was or was not *'provided with palliative care until death'*. The labeling of the patient served as the first inclusion criterion. As all deaths occured throughout the survey year, we had a varying follow-up time: some patients died in the first days of the survey, others died later in the study. To ensure that we had an observation period of at least three months for each patient, the second inclusion criterion was that the patient died at least three months after the start of the survey year.

Prescriptions

All prescriptions were derived from the prescription database of the DNSGP-2, which was connected to the data bases with the patient characteristics and the questionnaires,

and contained information about the Anatomical Therapeutic Chemical classification code (ATC-code) of the prescribed drugs.[24] We included all analgesics, with the exception of anti-depressants and neuroleptics, and classified them according to the three steps of the WHO analgesic ladder[11] by their corresponding ATC-code (see Table 1). Step 1 included all non-opioid analgesics: acetaminophen and NSAIDs. Step 2 included all weak opioids: codeine; tramadol and dextropropoxyphen. Step 3 included all strong opioids: morphine, fentanyl, and other strong opioids. When a drug with one ATC-code included two components from different steps of the WHO analgesic ladder, that drug was included in both steps. Of the adjuvant drugs prescribed to control adverse effects,[11] we included laxatives and antiemetics to investigate possible treatment of two adverse effects of opiods: nausea and constipation. Drugs and corresponding ATC-codes not listed in Table 1, were not prescribed during the DNSGP-2.

Measurements

- *Steps in the WHO analgesic ladder:* we analysed for each patient whether and if so when any drug from each of the three steps of the WHO analgesic ladder had been prescribed during the three months observation period before death.

- *First prescription:* each prescription was recorded as a first issue or a repeat prescription. A first prescription was defined as such when it was the first prescription in the three months observation period, and when the GP had not prescribed a drug from the same ATC-code in the six months before this first prescription. When a drug was first prescribed, the number of weeks between the date of prescription and the patient's death was calculated.

- *Combination with laxatives and antiemetics:* for each patient who was prescribed an opioid, we specified whether any laxative or antiemetic had been prescribed in the period an opioid was prescribed, and if so, whether the laxative was started before, or within three days after the start of the opioid. We did not distinguish between different types of laxatives or antiemetics.

Analysis

Descriptive analyses were carried out for patient characteristics and for the most frequently prescribed drugs in the three steps of the WHO analgesic ladder. Differences in prescribing between sub-populations were calculated at the start of the observation period, and over the last three months of life, for the characteristics sex, age and underlying disease, i.e. cancer versus non-cancer patients, using χ-square test ($\alpha = 0.05$). For all three steps, we longitudinally analysed the prescriptions in the total population by calculating the cumulative percentage of patients prescribed at least one drug in the three steps of the WHO analgesic ladder and patients prescribed nothing during the last three months of life, starting at 90 days before the patient's death. Further, we analysed the increase of analgesics prescribed during the three months observation period. When a patient was prescribed nothing or a step 1-drug, we analysed whether the prescribing of weak and strong opioids would have been appropiate according to the WHO analgesic ladder. Combinations of opioids with laxatives and antiemetics were calculated for the patients who were prescribed an opioid (WHO step 2 or 3).

Table 1.
Drugs included in the analysis and their corresponding ATC-codes and for pain medication classified according to the three steps of the WHO analgesic ladder.

Step WHO analgesic ladder / class of drug	ATC-code	Drug name
Step 1 WHO analgesic ladder	N02BE01	Acetaminophen
	N02AA59	Acetaminophen (+ codeine)
	N02BE51	Acetaminophen (+ other) (excl.psycholeptics)
	M01AE01	Diclofenac
	M01 (other)	Other NSAIDs
	N02BA	Salicylic acid + derivates
Step 2 WHO analgesic ladder	N02AA59	Codeine (+acetaminophen)
	N02BE51	Codeine (+acetaminophen)
	N02AX02	Tramadol
	N02AC04	Dextropropoxyphene
Step 3 WHO analgesic ladder	N02AA01	Morphine
	N02BA03	Fentanyl
	N02	Other
Laxatives	A06	
Antiemitics	A03FA	
	A04	

RESULTS

Of the 2,169 questionnaires sent to family physicians, 1,760 were returned (81%), and 1,596 were filled in completely (74% valid response rate). In total, 425 patients with an observation period of at least three months received palliative care from their family physician until death. Characteristics of the patients studied are presented in Table 2. Of all patients who received palliative care, 73% were prescribed at least one drug for pain during the observation period (Table 3). Of these patients, 31% received this prescription at the start of the observation period of 90 days before death. For most of these patients, the prescriptions were from step 1 of the WHO analgesic ladder, with acetaminophen prescribed for 14% of the patients. Drugs from step 2 and step 3 were already subsequently prescribed for 5.6% and 6.4% of the patients at 90 days before the patient's death. During the observation period, 55% of the patients received a step 1 prescription, 21% a step 2 prescription and 51% a step 3 prescription, with morphine and transdermal fentalyl as the most frequently prescribed drugs in step 3.
Of the analgesics which comprise step 1 of the WHO analgesic ladder, more cancer patients than non-cancer patients were prescribed diclophenac at 90 days before death, and over the full observation period. Also more cancer patients were prescribed tramadol over the full observation period than were non-cancer patients. More cancer patients than non-cancer patients were receiving a prescription for a strong opioid at 90 days before death and over the full observation period, with significantly more cancer patients being prescribed morphine and fentanyl over the full observation period.
Table 4 shows that at 90 days before the patient's death, there were no significant differences between the patients in different age categories, nor between males and females

Table 2.
Characteristics of the studied patients who received palliative care until death in family practice, with an observation period of at least three months (*n*=425).

	% (*n*=425)
Gender	
Male	47
Female	53
Age (years)	
< 70	28
70-79	24
80-89	32
≥ 90	16
Mean (SD)	76.9 (14.0)
Underlying disease [a]	
Cancer	55
Non-cancer	45
Heart failure	11
COPD	3.1
Other disease	26
Multiple non-cancer diseases	4.5

[a] Number of missing values for underlying diseases was 3.

Table 3.
Proportion of patients with drugs prescribed for pain during the last three months of life in patients who received palliative care until death in family practice in cancer and non-cancer patients and the total population (*n*=425).

A. Pain medication initiated before the observation period.

Prescribed drug	Cancer[a] (*n*=234)	Non-cancer (*n*=188)	*p* (χ-square)	Total (*n*=425)
No prescription (%)	65	73	0.113	69
At least one prescription (%)	35	27		31
Step 1 WHO analgesic ladder (%)	28	24	0.315	26
Acetaminophen (%)	15	13	0.675	14
Diclofenac (%)	12	5.3	0.017	9.2
Other NSAIDs (%)	7.3	7.4	1.000	7.3
Step 2 WHO analgesic ladder (%)	6.8	4.3	0.295	5.6
Codeine (%)	2.6	2.7	1.000	2.6
Tramadol + other[b] (%)	4.3	2.1	0.280	3.3
Step 3 WHO analgesic ladder (%)	8.5	3.7	0.047	6.4
Morphine (%)	5.6	2.1	0.085	4.0
Fentanyl (%)	4.7	2.1	0.192	3.5
Other (%)	0.4	0.0	1.000	0.2

B. Pain medication prescribed during the full observation period.

Prescribed drug	Cancer[a] (*n*=234)	Non-cancer (*n*=188)	*p* (χ-square)	Total (*n*=425)
No prescription (%)	19	36	0.000	27
At least one prescription (%)	81	64		73
Step 1 WHO analgesic ladder (%)	62	46	0.001	55
Acetaminophen (%)	39	34	0.312	37
Diclofenac (%)	29	13	0.000	22
Other NSAIDs (%)	17	11	0.095	14
Step 2 WHO analgesic ladder (%)	27	14	0.001	21
Codeine (%)	12	9.6	0.530	11
Tramadol + other[b] (%)	19	7.4	0.001	14
Step 3 WHO analgesic ladder (%)	62	37	0.000	51
Morphine (%)	39	24	0.001	32
Fentanyl (%)	45	20	0.000	34
Other (%)	5.1	1.6	0.064	3.5

[a] Number of missing values for underlying diseases was 3.

[b] One patient was prescribed dextropropoxyphene.

Table 4.
Proportion of patients who were prescribed at least one drug in each of the three steps of the WHO analgesic ladder by age category and sex in patients receiving end-of-life care in family practice (*n*=425).

A. Pain medication initiated before the observation period.

		No prescription	At least one prescription	Step 1 WHO analgesic ladder	Step 2 WHO analgesic ladder	Step 3 WHO analgesic ladder
Age Class (*n*=425)	<70 years (%)	72	28	22	6.8	9.3
	70-79 years (%)	69	31	26	5.0	5.9
	90-89 years (%)	65	35	29	7.4	5.9
	≥ 90 years (%)	71	29	27	1.4	2.9
	p (χ-square)[a]		0.557	0.290	0.329	0.090
Gender (*n*=425)	Male (%)	74	26	24	7.0	6.0
	Female (%)	65	35	28	4.5	6.7
	p (χ-square)		0.059	0.378	0.297	0.843

B. Pain medication prescribed during the full observation period.

		No prescription	At least one prescription	Step 1 WHO analgesic ladder	Step 2 WHO analgesic ladder	Step 3 WHO analgesic ladder
Age Class (*n*=425)	<70 years (%)	21	79	54	31	63
	70-79 years (%)	28	72	61	21	46
	90-89 years (%)	28	72	52	19	46
	≥ 90 years (%)	34	66	53	10	46
	p (χ-square)		0.060	0.581	0.001	0.014
Gender (*n*=425)	Male (%)	30	70	53	22	52
	Female (%)	25	75	57	21	50
	p (χ-square)		0.231	0.495	0.812	0.698

[a] χ-square for trend. Linear-by-linear association.

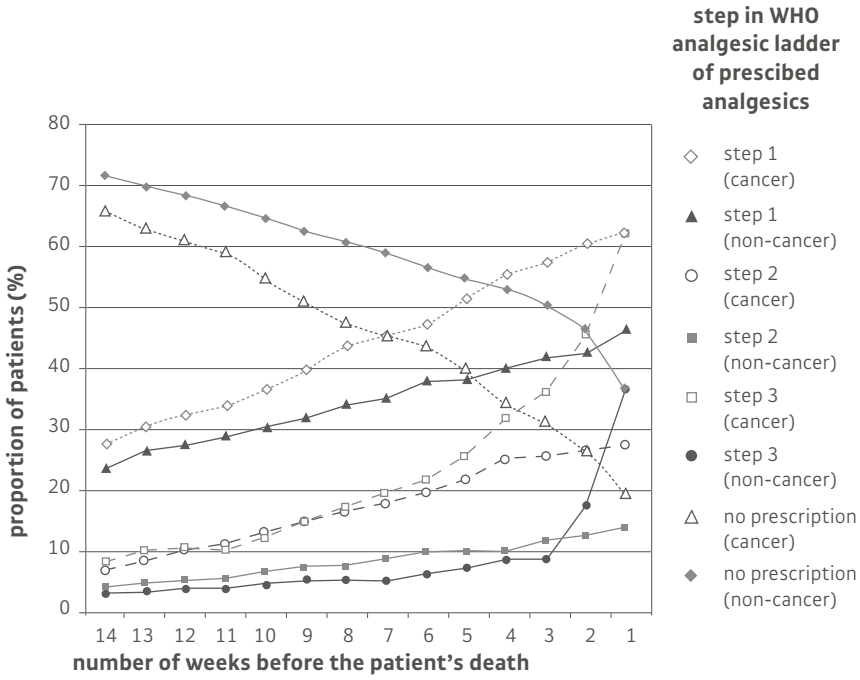

Figure 1.

Proportion of patients who were described nothing, and those prescribed at least one drug
In each of the three steps of the WHO analgesic ladder in the weeks preceding the patient's death (*n*=425).

in proportion to patients who received at least one prescription, a step 1, a step 2 or a step 3 prescription. During the full observation period, there were no differences by gender in the proportion of patients who were prescribed pain medication (Table 4). More younger patients were prescribed a strong opioid than were older patients.

Longitudinal development of prescribing during the last three months before the patient's death

Figure 1 shows the proportion of patients who were prescribed no drug, and at least one drug from each of the three steps of the WHO analgesic ladder in the weeks preceding death. At 90 days before death, the proportion of patients who had no prescription was 65% for cancer patients and 73% for non-cancer patients. This proportion descreased gradually towards the patient's death, with a steeper increase in the last week before death, resulting in 19% of the cancer patients and 36% of the non-cancer patients having received no prescription over the three months observation period (see also Table 3). At 90 days before death, the proportion of patients who received a step 1 prescription was 24 % for non-cancer and 28% for cancer patients. Towards the patient's death the proportion increased gradually, resulting in 46% of the non-cancer patients having received a step 1 prescription, and 62% of the cancer patients during the last three months of life (see also Table 4). The proportion of patients prescribed a

Table 5.
Prescribed pain medication during the last three months of the patient's before the patient's death and relation to the WHO analgesic ladder.

Step in WHO analgesic ladder	Total % (*n*=425)	Cancer patients % (*n*=234)	Non-cancer patients % (*n*=188)	Change according to the WHO analgesic ladder
No pain medication prescribed	27	19	36	Not relevant
Only Step 1	16	11	21	Yes
Step 1→ Step 2	2.8	3.4	2.1	Yes
Step 1→ Step 2→ Step 3	4.5	6.4	2.1	Yes
Step 1→ Step 3	16	20	11	No
Only Step 2	4.0	4.3	3.7	Unknown
Step 2→ Step 3	8.5	11	5.9	Unknown
Only step 3	22.1	25	18	Unknown

step 2 analgesic showed a similar gradual increase, with lower proportions of patients prescribed at 90 days before death and during the observation period of three months. For step 3 analgesics, the proportion of patients prescribed a strong opioid showed an exponential increase starting at three weeks before death for cancer patients, and one week later for non-cancer patients.

Prescribing according to the WHO analgesic ladder and co-medication to treat adverse effects

Table 5 shows that in the three month time frame, 16% were prescribed a step 1 analgesic during the observation period, and were not prescribed an analgesic from a higher WHO-step. Of the patients prescribed a step 1 drug, 40% received a step 3 prescription without having received a step 2 prescription, which is not in line with the WHO analgesic ladder. This occurred more frequently in cancer than in non-cancer patients (p=0.016). Of the 244 patients prescribed an opioid (step 2 and/or step 3), 17% were prescribed a laxative before the start of the opioid (data not shown). In 22% of all patients, the laxative was prescribed within three days of the prescription of the opioid, and in 14% more than three days after the start of the opioid. In 48% of the patients using an opioid, no laxative was being prescribed during the observation period, with no difference between oral and transdermal administration (p=0.142). A laxative was more frequently not prescribed to non-cancer patients than to cancer patients (60% v 41%; p=0.006). In total, 29% (n=70) of patients prescribed an opioid received a prescription against nausea, and of these prescriptions 34% were started more than three days after the opioid prescription.

DISCUSSION

Summary of main findings

In the last 90 days before death, 73% of patients receiving palliative care from their family physician were prescribed pain medication: 55% were prescribed a drug from step 1 of the WHO analgesic ladder (acetaminophen or NSAIDs), 21% a drug from step 2 of the ladder (weak opioids, e.g. codeine and tramadol), and 51% a drug from step 3 (strong opioids). Over the full period, more younger patients were prescribed a strong opioid, and more cancer patients were prescribed a drug from all three steps of the WHO analgesic ladder. There were no significant differences in prescribing by sex. During the last 90 days, the proportion of patients prescribed a step 1 or a step 2 drug increased gradually and the proportion of patients prescribed a step 3 drug increased exponentially, starting at three and two weeks before the patient's death for cancer and non-cancer patients, respectively. Of the patients who were prescribed a step 1 analgesic, 40% were prescribed a strong opioid without having been prescribed a step 2 analgesic. A total of 60% of non-cancer patients and 41% of cancer patients were prescribed an opioid without any prescribed laxative, and 14% of all patients were prescribed a laxative three or more days after the start of the opioid.

Strengths and the limitations of this study

Limitations of this study are that no information was obtained about the severity of the pain, and whether prescribing resulted in adverse events. Furthermore, we were unable to measure whether, in the prescriber's or the patient's opinion, pain control had been achieved. Also, we did not include drugs started before the 90-days observation period. As medication in The Netherlands is dispensed for a maximum of 90 days, this did not exclude medication that was intended to be used over the entire observation period.
This study was embedded in the second Dutch National Survey of General Practice, which has generated solid data due to its quality and size, and has allowed us to analyse the prescribing of pain medication longitudinally over the last three months before a patient's death. The total response rate of 74% for the additional questionnaire was high compared to mean response rates of 61% reported in studies carried out in general practice, and a trend of decreasing rates of response to mail questionnaires.[25] As most studies in palliative care are limited to cancer patients,[26] a further strength of this study is that we included both cancer and non-cancer patients.

Comparison with existing literature

A total of 27% of patients receiving palliative care in family practice, and 19% of the cancer patients, were not prescribed analgesics. Although pain is extremely common in cancer patients, studies report a wide variation in the prevalence of pain (33-88%).[27] The proportion of patients receiving a prescription for analgesics in our study is comparable to numbers found in other studies.[13,28] Weak opioids (step 2 of the WHO analgesic ladder) are prescribed to 27% of our cancer population, which is substantially lower than in the cancer population receiving care at home in Italy (52%)[13] and cancer patients treated at a pain center in Germany (60%).[29] This may be due to the fact that in both studies doctors were instructed to prescribe according to the WHO analgesic ladder. Our study shows that family doctors often pass over step 2 of the ladder. Although we have not collected data on the level of pain control, the exponential increase in prescriptions for strong opioids nearing the patient's death suggests a corresponding increase in pain. Our data suggest that for the optimal management of pain, some patients benefit from

the omission of step 2 of the WHO analgesic ladder, as advised in recent Dutch guidelines[30] and suggested by other authors.[12]
It is striking that the increase in opioid prescribing occurs in cancer as well as non-cancer patients, as pain is less common in non-cancer diseases. Possibly, non-cancer patients suffer a common increase in the need for strong opioids as patients, to manage pain and/or dyspnea.[31,32] It might also be that during the illness trajectory family doctors are reluctant to prescribe strong opioids for non-cancer patients, but when the end of life is near family physicians are more willing to prescribe the level of pain medication that the patient needs.[33,34]
A point of concern is the lack of prescribing of co-medication when prescribing opioids. Antiemetics are prescribed in only 27% of the patients. In 48% of the patients, no laxative has been prescribed and in 14% the laxative was initiated after the prescription of the opioid, suggesting the possibility that these patients were already constipated. The proportion of patients who are prescribed laxatives as co-medication is low, although this combination is advised in most guidelines.[11,35,36] Results from this population-based study show that family doctors do not act according to these guidelines. It might be that patients buy some laxatives without prescription over the counter. Possibly, it is difficult for the family physician to keep in mind the need for co-medication, and this aspect needs more attention in education and/or collaboration with pharmacists.[20] On the other hand, it might also be that there is a substantial proportion of patients who will not benefit from the prescription of laxatives, and family physicians in some way are able to discriminate between patients. The question of whether laxatives need to be prescribed to all patients using opioids is even more important to the non-cancer patients as 60% do not receive the laxatives they might benefit from.
Finally, we found that 34% of patients receive fentanyl via a transdermal patch. This could be an indication that GPs prescribe the fentanyl patch more often than advised in the WHO and EAPC recommendations, which prefer oral administration.[11,35] It appears that the practical advantages in the use of the transdermal patches for many patients and their GPs outweigh the advantages of oral dosing: a trend seen in other countries as well.[37]

Implications for future research or clinical practice
In total, 27% of the patients receiving end-of-life care in general practice are not prescribed analgetics. Further studies need to investigate why these patients are not prescribed analgesics: is it because there is no need for pharmacological management of pain, or is it because GPs do not adequately manage pain. To optimise pain management, we need to know why current practice with regard to the WHO analgesic ladder and the (lack of) prescription of laxatives differs substantially from guidelines. It cannot be ruled out that due to greater awareness and education in the last years, family practice has developed new insights into the optimising of pain management in palliative care patients, which are not reflected in the guidelines. Also, we need to know how we can optimally manage pain nearing end-of-life in non-cancer patients. Although they are difficult in design, detailed observational studies and/or randomised controlled trials are needed to answer these questions, and future education will preferably be based on the results of these studies.

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CHAPTER 5

A SURVEY ON GP COOPERATION IN PALLIATIVE CARE AT HOME

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ABSTRACT

- **Background:** Palliative care is considered to be a multidisciplinary approach. However, the extent of cooperation between GPs and other caregivers is unknown.
- **Objective:** To investigate the occurrence and determinants of cooperation between GPs and other caregivers in palliative care at home.
- **Methods:** For each patient who died during the one-year registration period (2000-2001) of the Second Dutch National Survey of General Practice, the relevant GP was surveyed on palliative care issues by an additional mail questionnaire.
- **Results:** Of all patients, 2,194 (0.6%) patients died during the study period. GPs returned 1,771 (73%) of the additional questionnaires. According to the GPs 743 (46%) of their patients received palliative care. In almost all patients (98%), the GP cooperated with at least one other caregiver, with a mean number of four others. Cooperation with informal caregivers (83%) was most prevalent, followed by cooperation with other GPs (71%) and district nurses (63%). The best determinants for cooperation between GPs and other caregivers were the patient's age, the underlying disease and the importance of psychosocial care in the care for the actual patient.
- **Conclusion:** In patients receiving palliative care, GP cooperation with other caregivers is highly prevalent, especially with informal caregivers and other primary care collaborators. Cooperation is more prevalent in younger patients, patients with cancer as underlying disease, and if psychosocial care is important in care for the actual patient.

INTRODUCTION

In the Netherlands, health care is characterized by a strong emphasis on primary care, where the GP is the central professional in the management and coordination of the patient's treatment.[1] Primary care also provides home care to the inhabitants of the homes for the elderly. Almost 60% of patients with non-acute illnesses die at home[2], and there is general consensus that palliative care should be provided in the patient's home, if possible.[3] The aging population and the growing number of non-acute deaths are expected to increase the GP's contribution to meeting the increasing need for palliative care.[4,5]

The World Health Organization (WHO) defines palliative care as: 'an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'.[6] Team work has been an integral part of the philosophy of palliative care[7] and is included in the WHO definition which further describes the content of palliative care as using 'a team approach to address the needs of patients and their families if indicated'.[6] Qualitative studies show that patients and GPs experience cooperation between GPs and other caregivers as an important aspect of palliative care.[8,9] A systematic review comparing interventions by teams in palliative and hospice care with usual practice showed benefits for the team approach.[10] Also, formal arrangements requiring GPs to work with specialist teams have been shown to improve outcomes.[11] However, the extent and level of cooperation in palliative care at home is unknown.

Some factors might predict GP cooperation with other caregivers. As both older and female patients receive less informal care[12], it might be expected that age and gender

may determine GP cooperation with others. In patients with greater pain and somatic problems, and in patients with psychosocial problems, cooperation may be more prevalent because multidisciplinary knowledge is needed to care for these patients. The aim of this study is to investigate the extent and the level of GP cooperation with other caregivers in palliative care at home and the determinants of that cooperation.

METHODS

Patients

The data used in this study were obtained from the second Dutch National Survey of General Practice, in which a representative sample of 96 Dutch general practices participated, with a total of 375,899 patients involved. The start of the one-year registration period of the study practices varied between April 2000 and January 2001.[13] The GPs received an additional post-mortem questionnaire designed for this study for each patient who died during the year of registration.

Measurements

We defined a 'palliative care patient' as those to whom the GP had provided palliative care. We also asked for underlying diseases. We assessed the importance in the care of the three palliative care domains included in the WHO definition: somatic care, psychosocial care, and spiritual care. The importance of these domains in the care for the actual patient was assessed on a five point likert scale (1=lowest importance of specific care item to 5=maximum importance). Finally, we asked the GPs to identify the level of cooperation in the care of each patient with the following caregivers: informal caregiver, colleague GP, district nurse (DN), specialist (physician), member of the home care team other than DN, pharmacist, social worker, physiotherapist, volunteer non-family caregiver, spiritual caregiver and other caregivers. GPs recorded the level of cooperation according to the following categories: none, incidental, and intensive.

Statistical analysis

We analysed GP cooperation with other caregivers in palliative care at the level of care for the individual patient. Descriptive statistics were computed for patient characteristics, importance of the three palliative care domains in care for the actual patient, GP cooperation with other caregivers, and the mean number of collaborators per patient. GP cooperation with other caregivers by patient characteristics and by the importance of palliative care domains in care for the actual patient was expressed using relative proportions. To test differences between groups ($\alpha = 0.05$), we calculated *p*-values of χ-square test.

We recoded scores of importance of palliative care domains in care for the actual patient into two categories: scores of 1, 2 and 3 were lumped together as 'not so important' and scores of 4 and 5 as 'important'. In the open text 'cooperation with another collaborator', homes for the elderly were frequently cited (*n*=104). We recoded GP cooperation with other caregivers as cooperation with homes for the elderly when cooperation with (a professional in) the homes for the elderly was recorded in the open text. Cooperation with social workers was not frequent (*n*=25). We removed cooperation with social workers and recoded this category as 'cooperation with another caregiver'. In the tables we use the recoded definitions of collaborators.

Logistic regression analysis was used to identify determinants for GP cooperation with other caregivers. Plausible interactions (e.g., gender by age, age by underlying disease,

underlying disease by importance of somatic care) were included. First, all possible determinants were tested univariately, after which the one with the highest p-value was entered into the model (α=0.05). This was repeated until addition of the next determinant did not improve the model significantly. To check for any change in the model, we varied this procedure. In the case of significant interaction, two models were presented. For each model, the R^2 was calculated to express the variation explained by the model.

RESULTS

In the 96 general practices 2,194 of the 375,899 patients died during the year of registration (0.6%). Of the 2,194 questionnaires sent to GPs 1,771 were returned (81%), and 1,608 were filled in completely, with regard to the identification of palliative care patients (73% valid response rate). These GPs worked in 86 general practices, and provided palliative care to 743 patients (46%). Table 1 shows the patient characteristics of the study population.

Table 2 shows the importance of palliative care domains in care for the actual patient. GPs perceived somatic care (mean score 4.1) as more important than psychosocial care (mean score 3.4) and spiritual care (mean score 2.1).

In almost all patients, GPs (98%) cooperated with at least one other caregiver (Table 3). The mean number of collaborators was near to 4 (median=4), with a mean of almost 1 intensive cooperation per patient.

Cooperation with informal caregivers (83%) was most prevalent, followed by cooperation with other GPs (71%), district nurses (63%), and specialists (55%). Intensive cooperation was most frequent between GPs and informal caregivers (63%), and incidental cooperation was most frequent between GPs and colleague GPs (60%).

In the case of male patients, more GPs cooperated with informal caregivers, DNs and specialists than in that of female patients, while with female patients, more GPs cooperated with homes for the elderly and spiritual caregivers than they did for male patients (Table 4). In case of younger patients, more GPs cooperated with informal carers, colleague GPs, DNs, specialists, home care other than DNs and pharmacists than in that of older patients. With older patients, more GPs cooperated with homes for the elderly. For cancer patients, more GPs cooperated with informal caregivers, DNs, specialists and pharmacists than with non-cancer patients. With non-cancer patients, more GPs cooperated with homes for the elderly and physiotherapists than in the case of cancer patients.

With patients for whom somatic care was 'important', more GPs cooperated with GP colleagues, specialists and pharmacists than in the case of patients for whom somatic care was 'not so important' (Table 5). With the exception of homes for the elderly, voluntary non-family caregivers and other caregivers, cooperation was more prevalent in cases where psychosocial care was 'important' than with patients for whom psychosocial care was 'not so important'. In patients for whom spiritual care was 'important', more GPs cooperated with specialists, voluntary non-family caregivers and spiritual caregivers than they did when spiritual care was 'not so important'.

Table 6 shows the significant factors in the model predicting GP cooperation with other caregivers in patients receiving palliative care. All models had relatively low values of the variation explained by the model. Being a female patient was a positive determinant for GP cooperation with homes for the elderly and spiritual caregivers. In informal caregivers, specialists and pharmacists we found the interaction between cancer as

Table 1.
Characteristics of patients receiving palliative care by their GP in the Netherlands (*n*=743)[a].

Age	**% (*n*)**
< 70 years	28 (207)
70-80 years	27 (196)
80-90 years	31 (228)
> 90 years	14 (106)
mean age, years [95% CI]	76 [61-91]
Gender	**% (*n*)**
Male	47 (349)
Female	53 (394)
Underlying disease	**% (*n*)**
Cancer	56 (412)
Non-cancer	44 (327)

[a] Number of missing values: age=6, underlying disease=4.

Table 2.
Importance of the three palliative care domains in care for the actual patient: somatic care, psychosocial care, and spiritual care (*n*=743)[a].

Importance of palliative care domains in care for the actual patient [b]		**% (*n*)**
Somatic care	not so important (1-3)	22 (152)
	important (4-5)	78 (580)
	mean score [95% CI]	*4,1 [3.1-5.0]*
Psychosocial care	not so important (1-3)	48 (350)
	important (4-5)	52 (380)
	mean score [95% CI]	*3.4 [2.3-4.6]*
Spiritual care	not so important (1-3)	85 (605)
	important (4-5)	15 (103)
	mean score [95% CI]	*2.1 [0.9-3.3]*

[a] Number of missing values for somatic care=11, psychosocial care=13, and spiritual care=35.

[b] Scores were assessed on a five point likert scale (1=low importance, 5 =maximum importance) answering the questions: *'in what degree was the following aspect important for the care of this patient? Treatment of somatic problems / psychosocial care / spiritual care.'* The scores 1-3 were recoded as 'not so important' and 4-5 as 'important'.

Table 3.
GP cooperation with other caregivers in care for patients receiving palliative care (*n*=743).

	Incidental cooperation[a]		Intensive cooperation[a]		Total	
	(*n*)	%	(*n*)	%	(*n*)	%
Informal caregiver	143	19	471	63	614	83
Colleague GP	449	60	77	10	526	71
District nurse (DN)	220	30	248	33	468	63
Specialist (physician)	302	41	109	15	411	55
Home care, other than DN	173	23	139	19	312	42
Pharmacist	163	22	26	3.5	189	25
Home for the elderly	28	3.8	76	10	104	14
Physiotherapist	67	9.0	6	0.8	73	9.8
Volunteer	38	5.1	18	2.4	56	7.5
Spiritual caregiver	44	5.9	10	1.3	54	7.3
Other caregiver	32	4.3	17	2.3	49	6.6
No cooperation					17	2.3
Mean number of collaborators [95%CI]		2.9 *[1.4-4.4]*		0.97 *[0.0-2.0]*		3.8 *[2.1-4.6]*
n total	743		743		743	100

[a] To determine cooperation we asked the following question: '*did you cooperate with the following carers while providing care to this patient?*' Answer categories were: no, incidentally and intensively.

Table 4.
GP cooperation with other caregivers in care for patients receiving palliative care by patient characteristics (*n*=743)[a].

	Gender			Age					Underlying disease		
	Male (%)	Female (%)	*p*	<70 (%)	70-80 (%)	80-90 (%)	90+ (%)	*p*	Cancer (%)	Non-cancer (%)	*p*
Informal caregiver	86	80	0.04	91	86	79	69	<0.001	89	75	<0.001
Colleague GP	69	72	0.32	73	75	71	58	0.02	74	68	0.07
District nurse (DN)	69	57	0.001	79	76	52	33	<0.001	77	45	<0.001
Specialist	62	50	0.001	73	64	45	25	<0.001	66	43	<0.001
Home care, other than DN	42	42	0.83	44	49	38	34	0.03	45	38	0.07
Pharmacist	28	24	0.22	35	27	20	17	< 0.001	31	19	<0.001
Home for the elderly	6.9	20	< 0.001		3.6	25	38	< 0.001	5.1	25	<0.001
Physio-therapist	8.9	11	0.42	6.8	13	9.6	10	0.19	4.9	16	<0.001
Volunteer non-family caregiver	6.0	8.9	0.14	5.3	8.9	4.8	5.7	0.19	9.0	5.8	0.11
Spiritual caregiver	4.9	9.4	0.02	9.7	5.6	7.5	5.7	0.40	7.0	7.6	0.75
Other caregiver	6.0	7.1	0.55	8.2	10	3.1	3.8	0.02	7.3	5.8	0.43
No Cooperation	1.1	3.3	0.05	9.7	8.7	4.8	5.7	0.14	1.5	3.4	0.086
n total	*349*	*394*		*207*	*196*	*228*	*106*		*412*	*327*	

[a] Number of missing values: age=6, underlying disease=4.

Table 5.
GP cooperation with other caregivers in care for patients receiving palliative care by the importance of palliative care domains in the care for the actual patient (*n*=743)[a].

	Somatic care			Psychosocial care			Spiritual care		
	Not so important (1-3) - %	Important (4-5) - %	*p*	Not so important (1-3) - %	important (4-5) - %	*p*	Not so important (1-3) - %	important (4-5) - %	*p*
Informal caregiver	80	85	0.12	80	87	0.01	83	88	0.21
Colleague GP	62	74	0.003	67	76	0.01	72	77	0.28
District nurse (DN)	59	65	0.17	55	73	<0.001	65	63	0.77
Specialist	48	58	0.02	48	64	<0.001	55	67	0.02
Home Care, other than DN	41	43	0.77	34	51	<0.001	42	47	0.35
Pharmacist	18	28	0.02	20	31	<0.001	26	29	0.52
Home for the elderly	12	15	0.35	20	8.4	<0.001	15	7.8	0.05
Physiotherapist	6.6	11	0.12	7.7	12	0.05	9.3	17	0.02
Volunteer non-family care giver	7.9	7.6	0.90	6.9	8.4	0.43	6.4	16	0.001
Spiritual caregiver	3.9	8.3	0.07	2.9	12	<0.001	4.6	25	<0.001
Other caregiver	7.2	6.4	0.70	5.4	7.6	0.23	6.6	6.8	0.95
n total	152	580		350	380		605	103	

[a] Number of missing values: somatic care=11, psychosocial care=13, and spiritual care=35.

Table 6.
Odds ratios of significant factors in models predicting GP cooperation with each other carer for patients receiving palliative care (*n*=743)[a]. Each line represents the significant factors for predicting GP cooperation with the specific collaborator.

	Patient characteristics[b]			Importance of the domains of palliative care		
Carer	**Gender**	**Age**	**Underlying disease**	**Somatic care (1-5)**	**Psychosocial care (1-5)**	**Spiritual care (1-5)**
Informal caregiver [c]						
Cancer patients		0.964 [0.939-0.990]				
Non-cancer patients					1.28 [1.04-1.58]	
Colleague GP				1.26 [1.07-1.48]	1.18 [1.11-1.50]	
District nurse (DN)		0.976 [0.962-0.990]	2.87 [1.99-4.12]		1.34 [1.15-1.55]	
Specialist [c]						
Cancer patients		0.979 [0.964-0.994]				
Non-cancer patients		0,923 [0,897-0,950]			1.35 [1.10-1.66]	
Home care, other than DN					1.44 [1.37-1.58]	
Pharmacist [c]						
Cancer patients						
Non-cancer patients		0.969 [0.949-0.990]				
Home for the elderly	1.836 [1.064-3.167]	1.139 [1.098-1.182]	0.48 [0.27-0.86]	1.53 [1.17-1.20]	0.78 [0.63-0.96]	
Physiotherapist			0.21 [0.12-0.37]	1.46 [1.10-1.94]		1.39 [1.14-1.69]
Voluntary non-family care giver						1.456 [1.18-1.81]
Spiritual caregiver	2.231 [1.191-4.178]			1.76 [1.21-2.56]		2.18 [1.73-2.73]
Other caregiver					1.51 [1.11-2.03]	

[a] Number of missing values: age=6, underlying disease=4, for somatic care=11, psychosocial care=13, and spiritual care=35.

[b] Gender: 1=male,2=female, an odds ratio >1 means greater odds for women; age (years), an odds >1 means greater odds for elderly; underlying disease: 0=non-cancer, 1=cancer; an odds ratio > 1 means greater odds for cancer patients.

[c] In these models we found interaction between cancer and age, so we presented 2 models: one for cancer patients and one for non-cancer patients.

underlying disease and age as significant factor in our initial model, hence we presented two models: one for cancer patients, and one for non-cancer patients. Age was a negative determinant in the models for informal caregivers (only cancer patients), DNs, specialists and pharmacists (only non-cancer patients). For predicting cooperation between GPs and homes for the elderly, age was a positive determinant. Cancer as underlying disease was a positive determinant in the model for cooperation between GPs and DNs; for the model predicting cooperation between GPs and homes for the elderly non-cancer was a positive determinant. Somatic care as important in care for the actual patient was a positive determinant for cooperation between GPs and colleague GPs, homes for the elderly, physiotherapists and spiritual caregivers. Psychosocial care as important in care for the actual patient was in many models a positive determinant; in the model predicting cooperation between GPs and homes for the elderly it was a negative determinant. Spiritual care as important in care for the actual patient was a positive determinant for cooperation with physiotherapists, voluntary non-family caregivers and spiritual caregivers.

DISCUSSION

In almost all cases of patients receiving palliative care at home in the Netherlands, the GP cooperated with at least one other caregiver, with a mean number of 3.8 collaborators. In patients receiving palliative care, GP cooperation with other caregivers is highly prevalent, with informal caregivers and other primary caregivers the most common. The best determinants for cooperation in palliative care between GPs and other caregivers were the patient's lower age, cancer as the underlying disease and psychosocial care as important in care for the actual patient.

This study was embedded in the second Dutch National Survey of General Practice, which has generated solid data due to its quality and size. Another strength of this study is the total response rate of 73% for the additional questionnaire, which is high compared to mean non-response rates of 39% reported in published studies carried out in general practice, and a trend of decreasing rates of response to mail questionnaires.[14] As most studies in palliative care are limited to cancer patients,[15] a further strength is that we included both cancer and non-cancer patients.

Limitations of this study are that no information was obtained about the content and frequency of cooperation nor about the criteria which motivated GP cooperation with other caregivers. Furthermore, we were unable to measure outcomes, hence we could not analyze any possible relation between quality of care and GP cooperation with other caregivers. We were also unable to search for association between GP cooperation and GP characteristics. All models predicting GP cooperation show relatively low values of the variation explained by the model, so it appears that GP cooperation is associated with many more factors than those included in this study.

To our knowledge, this is the first study that quantifies GP cooperation with other caregivers in palliative care patients. The results of this study show that in palliative care GPs seldom work alone. With a mean of four collaborators for each patient receiving palliative care, GPs contribute to the goal of palliative care as multidisciplinary approach.[6] In most patients the GP works with one collaborator at a level labelled as intensive, and in most cases this is the informal caregiver or the district nurse. However, with the aim of directing palliative care at 'the patient and their family'[6] cooperation with informal caregivers can be improved to meet the concerns of both patients and the

informal carers.[16] In 63% of the patients GPs cooperate with DNs. This is not considered to be low, as DNs are involved with more serious physical and psychosocial problems, or when technical bedside expertise is needed. GP cooperation with colleague GPs was only present in 55% of the patients. This is low as patient information is expected to be handed over after office hours. In the Netherlands over 90% of the population is covered by out-of-hours cooperatives.[17] It is possible that GPs take care for their palliative care patients themselves, or that GPs do not define handing over patient information as cooperation. Although this needs future exploration, it does question the quality of communication and continuity by the GP during out-of-office hours, a difficult area in palliative care at home.[18] Cooperation between GPs and homes for the elderly is characterised by more female and elderly patients, as might be expected due to the population living in homes for the elderly.

In contrast to our expectations, we found that in general GP cooperation with other caregivers is associated with the age of the patient and that patient's sex is no determinant. The most plausible reason is that because younger patients have more informal caregivers, they can stay longer at home with more complex diseases. GPs cooperated with others caregivers more in the case of cancer patients than in non-cancer patients. This may be because more caregivers are needed for symptoms that occur more frequently and are difficult to control.[19] However, this raises the question of whether older and non-cancer patients need such cooperation less or whether they are being excluded from something from which they might benefit.

The most striking determinant of GP cooperation with other caregivers is the importance of psychosocial care in care for the actual patient. This finding is difficult to interpret, as we have no data on the content of the collaboration. An explanation may be that the nature of the psychosocial problems itself may demand more communication and coordination,[20] or that the prevalence of psychosocial problems is intertwined with somatic issues.[21]

This study shows that cooperation between GPs and other caregivers is prevalent in almost all cases where patients receive palliative care from their GP. Present studies on communication in palliative care pay limited attention to interdisciplinary communication,[22] so future research should focus on the underlying problems that need cooperation, how caregivers communicate, and what possible barriers they meet. Our finding that few GPs cooperate with social workers and spiritual caregivers may mean that GPs deal with most social and spiritual problems themselves or that few patients have social or spiritual problems. However, also plausible is that patients and GPs themselves do not see it as the task of the GP to provide spiritual[23] or social care, or that GPs don't recognise or don't respond to these problems. Given the importance of spiritual and social aspects within palliative care,[24,25] these issues will need special attention in future studies.

More palliative care at home will be needed due to changing demographics and the changing face of primary care in Europe.[2] Given the complexity of palliative care and the diversity of problems that may require attention, the involvement of all necessary disciplines must be encouraged. On the other hand, the number of caregivers needs to be limited because patients and family prefer fewer caregivers and personal continuity.[2] One of the caregivers involved in palliative care must be responsible for the organisation of the involvement of all relevant disciplines. In palliative care at home, GPs or DNs could perform this task,[26] however there is still discussion on who should be in charge.[9,27,28] For the patient, this is less important as long as any competent caregiver will perform this task. All caregivers involved should make clear arrangements about

the use of available and needed expertise, responsibilities and communication; after all that is what cooperation is about.

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CHAPTER 6

GOOD END-OF-LIFE CARE ACCORDING TO PATIENTS AND THEIR GENERAL PRACTITIONERS

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ABSTRACT

- **Background:** Most patients prefer to die at home, where a GP provides end-of-life care. A few previous studies have been directed at the GPs' values on good end-of-life care, yet no study combined values of patients and their own GP.
- **Aim:** To explore the aspects valued by both patients and GPs in end-of-life care at home, and to reflect upon the results in the context of future developments in primary care.
- **Design of study:** Interviews with patients and their own GP.
- **Setting:** Primary care in the Netherlands.
- **Methods:** Qualitative, semi-structured interviews with 20 GPs and 30 of their patients with a life expectancy of less than six months, and cancer, heart failure or chronic obstructive pulmonary disease as underlying disease.
- **Results:** Patients and GPs had comparable perceptions of good end-of-life care.
- **Patients and GPs identified four core items that they valued in end-of-life care:** availability of the GP for home visits and after office-hours, medical competence and cooperation with other professionals, attention and continuity of care.
- **Conclusions:** Future developments in the organisation of primary care such as the restriction of time for home visits, more part-time jobs and GP cooperatives responsible for care after office hours, may threaten valued aspects in end-of-life care.

INTRODUCTION

In Western countries most people prefer to remain at home during the last part of their life, surrounded by their relatives.[1-3] In the Netherlands, health care is characterized by its strong emphasis on primary care: almost 100% of the inhabitants have their own GP who is the central professional in the management and coordination of the patient's treatment.[4] When needed, the GP initiates care at home by other professionals, like district nurses who provide nursing care, and home help for personal care. Almost 60% of patients with non-acute illnesses die at home,[5] and there is general consensus that end-of-life care should be provided in the patient's home, if possible.[6] The aging population and the growing number of non-acute deaths are expected to increase the contribution GPs must make to meet the rising needs for end-of-life care.[7,8]

The World Health Organization promotes palliative care as the preferred approach to improve the quality of life of terminally-ill patients and their families.[9] Several studies have evaluated the quality of care and the needs of terminally-ill patients in non-primary care settings. Qualitative and quantitative studies showed that terminally-ill patients considered emotional support, pain and symptom management, and accessibility as important aspects of the skills needed by physicians to providing end-of-life care.[10-12] In the Netherlands, two studies incorporated qualitative interviews to investigate the experiences of patients with cancer who received end-of-life care at home. In these studies it was found that pain and symptom management, attention, involvement and availability were important aspects of good end-of-life care.[5,13] Few studies have focused on the viewpoint of GPs with regard to the quality of end-of-life care, and those that did, were based on structured questionnaires. Hence, the aspects that were rated did not emerge from the GP's perspective. The GPs in these studies experienced care for dying people as rewarding and important.[14] To our knowledge, no single study has yet combined the values of both patients and their own GP with regard to end-of-life care.

In Europe, the structure and goals of primary care are changing: the population is ageing with a growing demand for health care on the one hand, while the relative number of caregivers decreases. GPs will work more frequently in primary care cooperatives and more GPs will work part-time.[15] These developments may threaten the core values of end-of-life care at home.

In order to investigate the nature of these core values of patients and their GPs with regard to end-of-life care, we conducted a qualitative study in primary care in which the viewpoints of both patients and their GPs regarding the quality of end-of-life care at home were described. The goal of this study was to explore the aspects valued in end-of-life care at home by patients and their GPs, and to reflect upon the results in the context of future developments in European primary care that may threaten these valued aspects.

METHOD

GP selection

A total of 17 GPs who were following an advanced postgraduate training in end-of-life care, organised by the Dutch College of General Practitioners,[16,17] agreed to participate in this study. To represent the opinions of GPs who were not trained in end-of-life care, and the opinions of their patients, we extended our sample: the GPs who agreed to participate were asked to invite a colleague of theirs in the same district with no specific interest in end-of-life care to participate. A total of 14 GPs with no specific interest in end-of-life care agreed to participate, resulting in a total number of 31 participating GPs.

Patient selection

After enrolment in the study, the GPs were asked to select for inclusion the first patient they encountered in their practice who met the following inclusion criteria: (1) a life expectancy of less than six months; (2) cancer, heart failure or chronic obstructive pulmonary disease (COPD) as underlying disease; (3) the GP was (one of) the primary caregiver(s), and (4) the patient had adequate command of the Dutch language. If for any reason, a GP did not approach a patient who met the inclusion criteria, the GP was asked to give the reasons for not doing so. If a patient met the inclusion criteria, the GP briefly described the study to this potential participant, and handed over an envelope containing an information sheet. The investigators then made an appointment with the patient to arrange an interview. Before the interview started the patient was asked to give informed consent. If the investigators could not make an appointment because the patient could not, or did not want to participate, the GP was asked to select the next patient who met the inclusion criteria. To include the potential range of opinions of patient views with different illnesses, we aimed to interview patients with the three most frequently presented terminal diseases in general practice: cancer, heart failure, and COPD,[5] with both male and female patients in each group.

Interviews

Semi-structured, in-depth interviews were carried out in the patients' home. Patients were interviewed for 45-80 minutes guided by a topic list (Box 1). During most of the interviews a partner or family member was present, and their comments were welcomed and included in the data. No information from the patient interview was made

known to the GP. Approximately two weeks after the patient interview the GP was interviewed according to a similar topic list. All interviews were audiotaped, transcribed verbatim, and rendered anonymous. The investigators read the transcript while listening to an interview to ensure textual accuracy. The transcripts of the interviews then served as data.
The interviews were performed by an academic researcher/pharmacist and a health sciences student. Prior to the interviews, both had followed an interview course, and during the entire interview period they were supervised by experienced qualitative researchers.

Analysis
All interview transcripts were analysed with support of QSR Nvivo 2.0, an established software package for ordering qualitative data. After 12 interviews, certain themes began to be repeated (data saturation). The investigators coded these first 12 transcripts independently to identify key themes, using the themes from the topic list and themes that the patients and the GPs considered to be important, as codes. In the subsequent interviews these themes were further developed until additional interviews provided no new information with respect to the research question. During the analysis, the authors ensured the validity of the results by critical discussion and searching for cases which seemed to verify or to conflict with the insights derived from the interim analysis.

RESULTS

Between January 2002 - August 2003, 20 GPs selected 31 patients who were receiving end-of-life care in their practices. In total, 11 GPs did not include any patients, six of whom were following the training in end-of-life care.

Patient characteristics
A total of 30 patients were included in the study: one patient could not be interviewed because her condition suddenly worsened. In the interviews the GPs reported that 13 patients had not been selected even though they met the inclusion criteria. The following reasons for not selecting a patient were given by the GP: very short life expectancy; cognitively, physically or emotionally not capable of being interviewed; communication problems between patient and GP; and denial of terminal illness.
During the study, patients with heart failure and COPD proved to be more difficult to recruit. As we had a limited time frame in which to hold the interviews, we asked all GPs, including those who had already included a patient, to select other patients who met the inclusion criteria and who had heart failure or COPD, in order to achieve our aim of including not only cancer patients, but also several patients with heart failure and COPD. In total 20 GPs included 30 patients: 14 GPs included one patient, three GPs included two patients, two GPs included three patients and one GP included four patients.
Table 1 summarises the characteristics of the patients and GPs who were interviewed. Half of the patient population was between 70 - 80 years old, and more males (63%) than females (37%) were interviewed. Of the 14 non-cancer patients, seven had heart failure, four had COPD and three patients had both underlying illnesses.

Box 1.
Topics of the interview.

Patient interview	GP interview
■ Disease history	■ Disease history
■ Experience with care at home performed by the GP	■ Gxperience with care at home for this patient
■ Good care performed by the GP	■ good care for this patient
■ The ideal GP	■ Good end-of-life care by the GP in general
	■ What patients had not been approached and why

Table 1.
Demographic, clinical and practice characteristics of interviewees (30 patients and 20 GPs).

	Patients (*n*=30)	GPs (*n*=20)
Male sex	19 (63%)	11 (55%)
Median age (range)	78 (49-93)	-
Underlying disease		
Cancer	16 (53%)	-
Non-cancer	14 (47%)	-
Median years of experience as GP (range)	-	20.5 (6-33)
Palliative care training	-	11 (55%)
Solo practice	-	8 (40%)

Aspects emerging from the analysis
The four items that were valued in end-of-life care by patients as well as GPs were availability of the GP for home visits and after office hours, medical competence and cooperation with other professionals, attention and continuity of care. The aspect of attention was more prominent in the patient interviews. There was no indication of any differences in the aspects that were mentioned by (patients of) GPs who were trained in end-of-life care and their counterparts who were not trained. The citations shown are exemplary for the opinions of the patients and the GPs.

Availability of the GP
Availability of the GP can be subdivided into the presence of the GP in the patient's home during home visits, and the availability of the GP after office hours. The interviews showed that most of the contacts between GPs and patients in end-of-life care were home visits:

'The doctor came in and sat down, quite relaxed. She asked if I had any complaints, if anything needed to be done. She asked about the home care services... After the death of my wife, she discussed everything with me. She took all the time in the world for me.' (Patient, male, 78, heart failure.)

This is a typical example of a home visit: by sitting down, the GP showed the patient that she had time, and then she enquired how things were going in general, and about

health-related issues in particular. The physical presence of the GP was a mixture of attention and interest.

The availability of the GP was experienced positively by the patient:

'That she's here whenever I need her. That's what I consider good care. You see, she comes here once a week. Spontaneously, you know.' (Patient, female, 49, breast cancer.)

GPs also considered regular home visits to be important.

'The most important thing [about good palliative care] *is that you visit them. That you're standing by, that they can call you, that there's no barrier. I always try to make an appointment for the next visit when I'm there. Then they know they can count on you.'* (GP, cared for patient, male, 71, colon cancer.)

In the interviews, the patients stressed the importance of the availability of a GP in case of an emergency, during the weekend, or at night. Patients appreciated it very much if they could reach their own GP in case of an emergency:

'When I need him, he's there for me. I don't need him that often. Nowadays that's different, but when I need him, he's there... I phone, or my children phone. I have his mobile number.' (Patient, female, 80, heart failure.)

Some GPs gave patients their mobile or home number so that they could phone in cases of emergency in the evenings and at the weekends:

'I've given him my home number so that he can call me. I'm not always at home in the weekends but when I'm there he can reach me. Because I think it's important for him to have peace.' (GP, cared for patient, male, 75, mesothelioma.)

Some patients reported a lack of care because their GP visited them rarely, although they could understand that their GP time was limited:

'Once in a while a doctor comes by, and she sees me quickly and then she's gone. We understand that they don't do everything for you nowadays ... but I really would appreciate it if the doctor visited me once every couple of weeks to check on how I'm doing.' (Patient, female, 77, heart failure.)

The GPs could not always satisfy the needs of their patients, due to lack of time and physical distance to the patient's home:

'The medical care is not bad, but I think more support is appropriate sometimes... I think supportive and emotional care is only sometimes sufficient in some cases. But I honestly think that counts for many of us. Because these are all home visits it's impossible to manage. For GPs, it's not reasonable any longer.' (GP, cared for patient, female, 78, heart failure.)

Medical competence and cooperation with other professionals

During the home visits the patients asked questions and told the GP about their medical problems and how they felt. Most patients described the GP's competence indirectly by expressing their satisfaction with interventions and medication. Some patients mentioned competence explicitly:

'A good GP, in this case doctor K, is someone who takes time to talk to you, even in these days, and someone who has adequate knowledge about my disease... She's very competent. That's what I consider very important.' (Patient, female, 84, breast cancer.)

GPs considered the treatment of physical and psychological symptoms to be an aspect of medical competence:

'For me at least, good palliative care is for me good medical care, it's good history-taking, carefully listening, a right diagnosis, and proper treatment.' (GP, cared for patient, male, 80, COPD and heart failure.)

According to the GPs, coordination of care and cooperation with other professionals were essential abilities of their medical competence in end-of-life care. GPs said they cooperated well with district nurses, the home care team, specialists and other GPs.

Patients who received care from multiple healthcare professionals mentioned that good end-of-life care was dependent on cooperation and communication:

'She [the GP] *takes everything quietly. She talks with the nurses about those pills: should we do this or should we do that? Well, that's it all about, isn't it?'* (Patient, female, 93, COPD and heart failure.)

However, some patients experienced problems with cooperation when too many professionals were involved, and/or when they were not communicating well with each other:

'It's difficult when you visit the hospital, and later the GP. It's far easier if you visit only the hospital or the GP. They work against each other. They have other ideas. This is from the hospital, that's from the GP. He [the GP] *says "let's try this* [medicine]*". Then you visit the hospital again and they disapprove.'* (Patient, female, 80, heart failure.)

The link between medical competence and continuity of care is demonstrated by the following citation. Home visits had both a social and a medical goal: not only did the GPs show involvement with the patient and the patient's family, they also dealt with current problems and could anticipate future problems.

'It's [the disease] *not predictable, like there's some kind of scenario ready to use. Each time you have to evaluate: what are the current problems and how do I have to manage these? Some things you can foresee, so you can anticipate.'* (GP, cared for patient, female, 55, breast cancer.)

Attention

Patients described attention from the GP as important element of good end-of-life care. They used terms such as, 'appropriate time', 'peace during the contact', as well as 'openness', 'honesty' and 'carefully listening'. They also thought that a GP should 'communicate respectfully' with them. The following citations contain some of these elements:

'[A good doctor is] *someone who listens, and accepts it when I'm down and takes time to listen to my story. Why am I terribly sad? And then, she tries to encourage me.'* (Patient, female, 72, heart failure.)

'[Good GP care is] *that he pays enough attention to you and doesn't rush in saying* "I can see it immediately". *And asks:* "What can I do for you and what are the problems. Do you feel anything or do you feel nothing?"' (Patient, male, 75, stomach cancer.)

The GPs did not describe attention as a separate or special element, but considered that attention for the patient and family was a normal aspect of the care provided:

'When I visit her, it's like visiting an acquaintance, we talk about the weather and how things are going, how the children are, and we just have a pleasant conversation. Then, the medical and technical things come up, and also the perception of her illness.' (GP, cared for patient, female 80, heart failure.)

Continuity of care

The GP's care for the patient usually started much earlier than the moment when the patient was diagnosed as terminally-ill - the patient and GP often shared a history:

'Any other one [GP] *could do the same* [care]*, but he wouldn't know that much about me. Through the years you develop a bond. And that's when you call each other to account, when you trust each other.'* (Patient, female, 53, blood cancer.)

The interviews revealed that the GPs also knew, and often provided medical care and support for the patient's partner and/or children. For example, one GP's care was influenced by knowledge about the patient's worries about a son with schizophrenia. Background information and a common history made end-of-life care easier, because the GP could interpret signals earlier and better:

'When you've already done things well, and you reach a certain situation you don't have to ask for information and you don't have to explore, then you can talk easier and fall back on things. You know the patient, the family, and the environment. Yes, that matters. I mean, with Miss A, we obviously went through a very intensive period after the death of her husband. That was totally different, but you know the whole family.' (GP, cared for patient, female, 86, breast cancer.)

A shared history, specific medical knowledge about the disease, the background and family knowledge, were reasons why most patients preferred to be visited by their own GP. In some cases, familiarity with their own GP was a reason to postpone consultation:

'When we have to call for another doctor, well, we don't like that. I don't want that. We don't like all those strange doctors, and they don't know anything about my husband. Well, we'd rather wait till our own GP can come.' (Partner of patient, male, 75 stomach cancer.)

DISCUSSION

Summary of main findings

Patients and GPs identified the same four core aspects valued in end-of-life care: availability of the GP for home visits and after office-hours, medical competence and cooperation with other professionals, attention and continuity of care. These values were identified by patients and their own GP, and by cancer patients as well as by non-cancer patients.

Comparison with existing literature

The four core aspects valued in end-of-life care: availability of the GP for home visits and after office-hours, medical competence and cooperation with other professionals, attention, and continuity of care: were identified separately in different patient populations,[18,19] or by carers for terminally-ill patients.[20] This is the first study where these values were found together, identified by patients and their own GP, and by cancer

patients as well as by non-cancer patients. The aspects valued in end-of-life care are comparable with those found in chronically ill patients.[21,22]
The ability to coordinate care and cooperate with other health care professionals is an essential part of the competence of the GP, because end-of-life care at home is a team approach.[23] The problems we found regarding cooperation and communication between health professionals, confirm the findings from other studies and show that these problems may be felt by patients. This confirms, once again, the paramount importance of the quality of collaboration between GPs and other health professionals,[24] and of optimal interdisciplinary communication recognising the specific contribution of each professional.[25]
Some authors have tried to combine the results from different studies in a conceptual framework for good end-of-life care. Stewart *et al*. identified in their quality of life model three factors that determine quality of life in terminal care: (1) fixed patient and family factors, not amenable to change, (2) structure and process factors, and (3) outcome factors.[26] The aspects mentioned by the patients and GPs in our study are also present in Stewarts model. Availability of the GP for home visits and medical competence are part of the categories of structure and process of terminal care. Attention is related to communication and interpersonal skills, which are elements of the process of terminal care. Continuity is also included in the (technical) process factors. The aspects we found are all at the level of structure and process of care; we found no outcome-related aspects of good end-of-life care. In our study, potential results of GP interventions, such as less pain or better symptom control, were less emphasised than the availability of the GP. One reason might be that the patients expected that GPs who were in the patients' opinion medically competent, would achieve good control of pain and symptoms, or the lack of outcomes mentioned by the patients might be that the patients considered the importance of outcomes to be obvious. It might also be the opposite: the failure of health care to cure their illness or failure to achieve pain control in the hospital, may possibly have led to low expectations with regard to outcomes of care at home.
Within their framework, Stewart *et al*. focus on outcome factors of terminal care, such as quality of life. Our findings suggest that their framework should be shifted to focus more on process and structure categories. With the increasing pressure from government and health care funding agencies to evaluate the quality of the care that is provided,[15] evaluations should not only be directed towards outcomes, but should also include the domains of structure and process.

Strengths and the limitations of this study
Strengths of this study were that we included both GPs with and without special interest in end-of-life care, and patients with cancer as well as non-cancer patients. The researchers were not involved in providing end-of-life care themselves and interviewed the patients and their GPs according to a similar topic list. A limitation of this study was that the patients were terminally-ill and largely dependent on their GP. This situation might limit free expression of thought, although we assured the patients that the information would remain confidential and that confidentiality was also assured for their own GP. Secondly, the GPs confirmed that they had made a selection of patients who they thought were suitable to be interviewed. Some GPs did not approach patients if the GP-patient communication was difficult, and did not approach patients who were in an instable phase of their illness. Hence, we probably interviewed the patients who were relatively healthy and who were satisfied with their GP. Patients who are less satisfied

and who are unstable may value different aspects, such as achieving pain control, because they may have a greater risk of poor symptom control.

Implications for future research or clinical practice

Our study does raise some questions about the quality of future end-of-life care at home. Aspects valued in our study might be subject to developments in primary care which will change care at home and the role of the GP. First, home visits and adequate time for doctor-patient contacts are already under pressure.[27] Home visits without a specific intervention as a goal might not be covered by health insurances, and even if they are, the single rate that applies does not include the extra time needed for end-of-life care. Although GPs consider end-of-life care to be rewarding, and an important aspect of primary care,[14] they might be less willing to care for end-of-life patients if their efforts are not financially reimbursed.

Secondly, in primary care there are developments favouring more part-time jobs, wider career possibilities, fewer solo practices and local cooperation of GPs, especially with respect to after-office-hours services.[15,28,29] This is a threat for the personal continuity and after-office-hours services for end-of-life care patients.[30-32] It will be more difficult to organise personal continuity for part-timers, especially after office hours. The wider career possibilities will make it easier for GPs to move to another practice during their career, and this will also decrease the duration of patient-doctor contacts.[29] Large-scale organisation of after-office-hours services by GP cooperatives will probably not only decrease the number of visits after office hours, but will also imply that these visits will be made by a GP who is unfamiliar with the patient and the family. These developments are a challenge for general practice to find a way to both organise a modern primary care system, and to continue to provide good end-of-life care at home according to the valued aspects: availability of the GP for home visits and after office hours, medical competence, attention and continuity of care.

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CHAPTER 7

COMMUNICATION ABOUT EUTHANASIA IN GENERAL PRACTICE: OPINIONS AND EXPERIENCES OF PATIENTS AND THEIR GENERAL PRACTITIONERS

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ABSTRACT

- **Objective:** public opinion and professional organisations dominate the euthanasia debate, and there is a need to understand the opinions of people confronted with euthanasia. The aim of this study was to investigate whether patients and their GPs talk about euthanasia, and if so, how they communicate about this.
- **Methods:** qualitative, semi-structured interviews were held with 20 GPs and 30 of their patients in primary care in the Netherlands, where euthanasia is legalised. The patients had a life-expectancy of less than six months, and cancer, heart failure or chronic obstructive pulmonary disease as underlying disease.
- **Results:** many patients did not communicate about euthanasia with their GP. Neither the patient nor the GP were clear in formulating their expectations concerning future decision making.
- **Conclusion:** the initial patient-GP communication consisted of an exchange of opinions about situations in which euthanasia would be desirable. GPs had different opinions about who should initiate communication, and found it difficult to judge the right moment to talk.
- **Practice implications:** it is essential to pay attention to education in communication about dying and euthanasia and to train the GPs to gain insight in the patient's end-of-life preferences, and to direct care at the best possible quality of life.

INTRODUCTION

Health care in the Netherlands is characterized by a strong emphasis on primary care, where the GP is the central professional in the management and co-ordination of the patient's treatment.[1] Almost 60% of patients with a non-acute illness die at home,[2] and there is general consensus that palliative care should be provided there.[3] In 2001, death was preceded by end-of-life decision-making in approximately 40% of all cases.[4] While 7% of patients had made an explicit request for euthanasia or assisted suicide, 2.6% of all deaths were the result of euthanasia. GPs performed euthanasia more frequently than all other doctors.[4]

In the Netherlands, euthanasia is legal and is defined as an act, undertaken by a third party, which intentionally ends the life of a person at his or her request.[5] This decision is taken within the doctor-patient relationship, and societal control has been incorporated into post-death review procedures.[6] Prudent practice is required of doctors and this includes the patient being well informed about diagnosis, prognosis, and treatment options.[6] Moreover, both doctor and patient must be convinced that there is no other reasonable option. In this process, communication between patient and doctor is essential.

The status of euthanasia in relation to palliative care is not clear: some authors claim that euthanasia can be part of palliative care[7], but most argue that there is no place for euthanasia in palliative care.[8] The same standpoint is adopted in the World Health Organization (WHO) definition which states that palliative care 'intends neither to hasten nor postpone death'.[9] The European Association of Palliative Care (EAPC) ethics task force says that 'individual requests for euthanasia require respect, careful attention, together with open and sensitive communication', and 'provision of euthanasia should not be part of the responsibility of palliative care'.[10] This makes the status of communication about euthanasia in palliative care ambiguous: while the two are considered

incompatible, communication becomes essential. More insight is essential for a better understanding of the complex relationship between euthanasia and palliative care.
In the current debate on euthanasia where the voices of professional organisations and politicians have been dominant, there is need for more understanding of the subjective experiences of those involved.[11] Due to legalisation in the Netherlands, euthanasia can be one potential result of the communication process. In this context, we investigated the opinions of doctors and patients regarding good end-of-life care, using a qualitative design in primary care.[12] This paper investigates an important research question that came up during that study: do terminally-ill patients and their GPs talk about euthanasia and, if so, how do they communicate about it, for instance about what topics and on whose initiative.

METHODS

GP selection

Of 49 GPs following an intensive postgraduate course in end-of-life care, organised by the Dutch College of General Practitioners,[13,14] 17 agreed to participate in this study. To represent the opinions of GPs who were not trained in end-of-life care, and the opinions of their patients, we extended our sample: the GPs who agreed to participate were asked to invite a colleague in the same district with no specific interest in end-of-life care to participate also. A total of 14 GPs with no specific interest in end-of-life care agreed, resulting in 31 GPs taking part, 20 of whom included one or more patient.

Patient selection

After enrolment in the study, the GPs were asked to select for inclusion the first patient they encountered who met the following criteria: (1) a life-expectancy of less than six months; (2) cancer, heart failure or chronic obstructive pulmonary disease (COPD) as underlying disease; (3) the GP as (one of) the primary caregiver(s); and (4) an adequate command of the Dutch language. GPs who, for any reason, did not select a patient who met the inclusion criteria, were asked to give their reasons for not doing so. If a patient met the inclusion criteria, the GP briefly described the study to them, and handed over an envelope containing an information sheet. The investigators (SDB and CGR) then made an appointment with the patient for an interview. Before the interview the patient was asked to give informed consent. If the patient could not or did not want to participate, the GP was asked to select the next patient who met the inclusion criteria. We aimed to include the opinions of both cancer patients and patients with the other two terminal diseases most frequently presented in general practice: heart failure and COPD.[2]

Interviews

Semi-structured, in-depth interviews were carried out in the patient's home. During most of these interviews a partner or relative was present. The interviews with the first 12 patients and those with their GPs, started with the goal of exploring the aspects of end-of-life care at home most valued by both patients and GPs.[12] As is usual in qualitative research, interim analysis, steered subsequent data-collection and analysis. During the interim analysis we found that communication about euthanasia was an interesting topic in most interviews. In subsequent interviews, we aimed to investigate this further, and therefore added the following questions: *(1) did you talk (with your GP / with your patient) about euthanasia, and in the GP interviews (2) how do you communicate*

with patients in general about euthanasia? If the answer to the first question was positive, we asked the interviewee to elaborate.
Approximately two weeks after the patient interview, the GP was interviewed according to a similar topic list. No information from the patient interview was revealed to the GP. All interviews were audio-taped, transcribed verbatim, and rendered anonymous. The investigators read the transcript while listening to the interview to ensure textual accuracy. The transcripts of the interviews then served as data.
The interviewers were an academic researcher/pharmacist (SDB) and a health scientist (CGR). Prior to the interviews, both had followed an interview course, and during the interview period they were supervised by experienced qualitative researchers (ALF and DLW).

Analysis
All interview transcripts were analysed with the support of QSR Nvivo 2.0, an established software package for ordering qualitative data. The fragments concerning euthanasia from all interviews were identified and coded by the two researchers according to themes that patients and GPs considered to be important. During the analysis, the validity was ensured by critical discussion and by searching for cases which seemed either to verify or contradict the insights derived from the interim analysis.

RESULTS

Patient characteristics
Between January 2002 and August 2003, 20 GPs recruited 31 patients receiving end-of-life care; one patient could not be interviewed because her condition suddenly worsened. A total of 11 GPs, six of whom were on the end-of-life care course, did not recruit any patient. In the interviews the GPs reported that 13 patients had not been selected, even though they met the inclusion criteria. They gave the following reasons for not selecting a patient: very short life-expectancy; cognitively, physically or emotionally unable to be interviewed; communication problems between patient and GP; and denial of terminal illness.
During the study, patients with heart failure and COPD proved to be more difficult to recruit. As we had a limited time-frame in which to hold the interviews, we asked all GPs, including those who had already included a patient, to select other patients with heart failure or COPD who met the inclusion criteria in order to achieve our aim of including not only cancer patients. As a result, 14 GPs each included one patient, three GPs included two patients, two GPs included three patients and one GP included four patients.
Table 1 summarizes the characteristics of the patients and the GPs who were interviewed. Half the patients were between 70 and 80 years old, and more men than women were interviewed. Of the 14 non-cancer patients, seven had heart failure, four had COPD and three had both illnesses. In 25 patient-interviews euthanasia was a topic, and in 14 of these the patient and GP communicated about euthanasia (Table 2).

Aspects emerging from the analysis
Four main aspects of communication about euthanasia emerged from the interviews: (1) many patients did not communicate about euthanasia, (2) future decision making, (3) clarifying and fine-tuning, and (4) initiative and timing.

Table 1.
Demographic, clinical and practice characteristics of interviewees (30 patients and 20 GPs).

	Patients (*n*=30)	GPs (*n*=20)
Male gender	19 (63%)	11 (55%)
Median age (range)	78 (49-93)	-
Underlying disease		
Cancer	16 (53%)	-
Non-cancer	14 (47%)	-
Median years of experience as GP (range)	-	20.5 (6-33)
Palliative care training	-	11 (55%)
Solo practice	-	8 (40%)

Table 2.
Patient and GP characteristics of all patients who mentioned euthanasia in the interview (*n*=25).

	Did patient and GP communicate about euthanasia?		All patients who mentioned euthanasia in the interview (*n*=25)
	Yes (*n*=14)	No (*n*=11)	
Patient characteristics			
Underlying disease:			
cancer	10	2	12
non-cancer	4	9	13
Gender			
male	10	6	16
female	4	5	9
Age			
> 78 years	7	3	10[a]
≤ 78 years	7	8	15
GP characteristics of these patients			
Training in palliative care			
Yes	9	9	18[b]
No	5	2	7
Years of experience			
> 20	6	5	11
≤ 20	8	6	14

[a] Most younger patients had cancer (*n*=6 out of 10) and most older patients did not have cancer as underlying disease (*n*=9 out of 15).

[b] GPs trained in palliative care included more non-cancer patients (*n*=11 out of 18), and GPs not trained in palliative care included more cancer patients (*n*=5 out of 7).

Most quotations concerning euthanasia were from GPs. These reflect their experiences with euthanasia during their career, but do not necessarily involve communication with the patient(s) they had included in this study. The reason for this was that the patient and the GP had often not had extensive communication about it. The GPs found that problems around euthanasia usually arose closer to the end-of-life. There was no indication that whether the GP was or was not trained in end-of-life care made any difference.

Many patients did not communicate about euthanasia

Table 2 shows that 11 out of 25 patients did not communicate about euthanasia. For many patients euthanasia was not an issue in their end-of-life trajectory, and therefore they did not feel it was necessary to talk about it. Sometimes patients had religious reasons for not wanting to talk about euthanasia:

I don't want to talk about euthanasia. Man proposes, God disposes. There's nothing to decide about. (Patient, male, 78, COPD and heart failure.)

GPs said they often did not initiate communication with patients who were religious. However, there were religious patients who wanted to talk about euthanasia, and requested euthanasia.

Table 2 also shows that communication about euthanasia was more frequent with cancer patients than with non-cancer patients. This matched the experiences of GPs, that euthanasia was more frequently a topic of communication with cancer patients:

With them [patients with COPD or heart failure] *you tend less to talk about euthanasia. Studies show how difficult it is to predict when someone with heart failure or COPD will die. And to say to them a year before they die: 'what would you prefer when things get worse?', that's something you don't do. So it might sound strange, but it doesn't happen.* (GP, cared for patient, male, 82 years heart failure.)

Future decision making

In one interview, communication concerned an actual request for euthanasia. All other communications concerned future decision making. Patients and GPs exchanged opinions about situations which could give rise to euthanasia requests. In some cases the communication was a (written) statement from the patient that he no longer wanted to live if the suffering was unbearable. Handing over a written request was not experienced as proper communication by one GP; a detailed discussion was a prerequisite to the communication process.

When talking about euthanasia, patients had in mind situations in which their life would no longer be worth living. They often had an idea about how they did or did not want to die. The fear they expressed involved physical aspects of suffering such as pain:

I wrote a request for euthanasia in the presence of Dr. E., she signed it, and I also signed it. She's willing. I just wrote down that if I become paralysed, or if the pain is unbearable, and if I become a poor, little, ill woman, confined to bed, then she is prepared to give me euthanasia. (Patient, 55, female, breast cancer.)

However, not all requests from patients were as clear as this. GPs were confronted by rather vague, more general requests:

Patients often make indirect statements such as: 'Doctor, you won't let me down, will you?' Well, what do they mean by such a statement, and how should we react? What do they expect? (GP, cared for patient, 55, female, breast cancer.)

GPs mentioned that patients did not only speak about euthanasia; discussion was accompanied by exploring other end-of-life situations which provided insight into the patient's end-of-life preferences.

Clarifying and fine-tuning

In a typical response to a request, GPs promised they would support patients in the performance of euthanasia, on the condition that when the situation arose, the GP and the patient must both agree that it was the best option:

> *Quite soon* [after the diagnosis] *the possibility of euthanasia was discussed in detail with him and his wife. He clearly stated that he didn't want to go through hell and that when life really becomes unbearable, he will ask me for* [active] *euthanasia. I agreed, on the condition that I must also be convinced.* (GP, cared for patient, 60, male, lung cancer.)

Neither the patients nor the GPs were very clear in formulating their expectations about the conditions under which euthanasia would be performed. The following quote illustrates that communication often involved a general exchange of expectations:

> *We talked about it (euthanasia) and my GP agrees. 'Not for some time', she says, 'at the moment, you can still handle it.' But as soon as it becomes too bad, I will say: 'please bring this to an end.'* (Patient, 86, male, stomach cancer.)

An important aspect of communication was the clarification of the euthanasia question. What do the words 'unbearable' or 'inhumane' mean? Do patient and GP have the same view of what would justify euthanasia? One GP foresaw a potential dilemma. The patient and GP had not yet explored their views on what they meant by 'unbearable', hence it was unclear what they expected from each other:

> *I told him that if the suffering really becomes unbearable, I think that he should not have to live any longer, but that I would do anything to make his life bearable. There are many possibilities, but I haven't met a patient whose life became unbearable. At that moment we were both satisfied, and he had no further questions. It might become a problem when we reach a situation in which I think life is still worth living, and he doesn't.* (GP, cared for patient, 75, male, mesothelioma.)

Monitoring changes in opinion during the illness trajectory was important. A patient who said that she wanted euthanasia at the onset of her disease, changed her mind during the illness trajectory. Her GP expected that in the end, she would not require euthanasia.

Initiative and timing

Most GPs left the initiative to talk about euthanasia to their patients, but were sensitive to signals that might indicate a patient's wish to talk:

> *I have developed the policy that as long as people don't raise the subject* [euthanasia] *themselves, I won't be the one to start talking, although I am sensitive to signals. As soon as there is any indication, I will raise the subject.* (GP, cared for patient, 75, male, oesophagus cancer.)

Other GPs initiated the subject when they foresaw problems in the near future:

> *Whether I raise the topic of euthanasia, depends on the situation. For example, with someone who has larynx carcinoma that can close up the throat, I raise the topic sooner*

and more actively in case that occurs. Then everybody knows: what is preferred in that case. (GP, cared for patient, 80, male, COPD.)

GPs stated that it was difficult to judge the right moment for communication about euthanasia. Some GPs took initiatives themselves to plan future activities, to co-ordinate care, and to communicate about the patient's preferences.

Another aspect according to some GPs was that they wanted to be sensitive and talk about the subject without suggesting that they promoted euthanasia:

When the end of life is near, I want to make euthanasia a topic of consideration. However, I don't want to put the words into their mouth. I'm always afraid that people will feel: 'I must have euthanasia or else I'll be a burden for the doctor or for everybody else.' A request for euthanasia must come from the people themselves, when they feel there's no way out. (GP, cared for patient, 68, male, lung cancer.)

Both patients and GPs acknowledged that it was an advantage if the GP had known the patient for a longer period and shared a common history, and if they could communicate in the patient's home.

DISCUSSION AND CONCLUSION

Discussion

We interviewed patients and GPs in one of the few countries in which euthanasia is legalised. Patients prepare themselves for a (worst case) scenario in which they might consider euthanasia. At the same time, GPs also anticipate the worst case scenario: a situation in which they are requested to administer lethal drugs. GPs had different opinions about whether they should initiate communication, and found it difficult to judge the right moment to do so.

The strengths of this study is that we interviewed both patients and their GPs, using a similar topic list. We included GPs with and without special interest in end-of-life care, and patients with cancer and non-cancer as underlying disease. We assured the patients that the information would remain confidential and that confidentiality was guaranteed to their own GP.

Obviously, our study has some limitations. The GPs admitted that they had selected patients who they thought were suitable to be interviewed. Hence, we probably interviewed patients who were relatively healthy and satisfied with their GP. Due to good patient-doctor contact, euthanasia might be easier to talk about, and the GP more sensitive in reacting to signals. GPs mentioned their experiences with communication about euthanasia during their careers, while one interview was held with each patient. Hence, we collected more data on the experiences of GPs than of patients. Yet, given these limitations, we are of the opinion that they do not change the meaning of our findings.

In other countries, apart from Belgium, the performance of euthanasia is illegal and communication about euthanasia is less frequent.[15] In studies directed at end-of-life communication the main barriers doctors identified were associated with the timing of communication,[16] an aspect also found in our study. Most of the GPs we interviewed were careful, and some were reluctant, to initiate communication about euthanasia, and approximately half of the patients communicated with them on this subject. In the

context of euthanasia as one of the end-of-life options, we might have expected more communication.
We also expected that more GPs would have initiated communication, because patients should be informed about all possible options to enable them to make informed decisions.[17] It seems that the fact that euthanasia is legal does not make it any easier to initiate communication about it. In our opinion, open communication may result in agreement between patient and doctor on whether to perform euthanasia or not. With this in mind, it is unclear what the EAPC and WHO mean by open communication about euthanasia in the context of the explicit exclusion of the act.[9,10]

Conclusion
The initial communication between patient and GP consists of an exchange of opinions about possible situations in which euthanasia is desirable. GPs have different opinions about whether communication should be initiated by the patient or the GP, and find it difficult to judge the right moment to talk about euthanasia.

Practice Implications
Since talking about death is experienced as difficult by doctors,[18] it is essential to pay more attention to training in communication about death, dying and euthanasia.[19] Communication should be directed at end-of-life decisions that are allowed in each specific regional setting. Not only to make good decisions, but also to gain insight in the patient's end-of-life preferences that will allow doctors to direct care towards the best possible quality of life and death.

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CHAPTER 8

GENERAL DISCUSSION

INTRODUCTION

The objective of this thesis was to investigate issues of current practice in end-of-life care in general practice in the Netherlands. Our main aim was to study epidemiological issues of end-of-life care in general practice: needs of patients receiving end-of-life care, indicators of quality of end-of-life care by the GP, and organisation of end-of-life care at home. We also aimed to explore the opinions of patients and their GPs. This chapter will discuss the methodology of the studies, examine the main results in the context of current literature and describe the implications for future research, practice and policy.

METHODOLOGICAL CONSIDERATIONS

In this thesis, we used two different types of data collection. Quantitative results were attained by combining the data collection of the second Dutch National Survey of General Practice (DNSGP-2) with an additional end-of-life care questionnaire. The latter was also used to identify the patients receiving end-of-life care. Qualitative data were obtained by performing interviews with 30 patients receiving end-of-life care at home, and their general practitioners. In order to discuss the impact of the chosen study design and analysis on the results, we will describe the main strengths and weaknesses of our studies.

Dutch National Survey of General Practice

Our study was embedded in the second Dutch National Survey of General Practice (DNSGP-2), a nationwide study of doctor-patient contacts in a representative sample of general practices in the Netherlands.[1] This study generated complex and solid data about end-of-life care in general practice in the Netherlands. With the availability of this extensive database we selected the data relevant to the study of: needs of end-of-life patients, quality of end-of-life care by the GP, and organisation of end-of-life care at home.

The data in the DNSGP were collected prospectively. We were able to analyse patient-GP contacts and prescribing of pain medication over a three month period preceding death. A further strength of this study is the total response rate of 73% to the additional questionnaire, which is high compared to mean response rates of 61% reported in published studies carried out in general practice, and a trend of decreasing rates of response to mail questionnaires.[2] As most studies in end-of-life care are limited to certain settings and to cancer patients[3] a further strength is that this study is population based, hence including both cancer and non-cancer patients.

However, this study had some limitations. The DNSGP-2 was not designed specifically for end-of-life research, so there were no data available on several items that are relevant for end-of-life care. For example, there were no data available on the need for palliative care, the level of symptom control and whether the management by the GP resulted in improvement of symptom control. Also, we measured symptoms that were prevalent in encounters according to physicians. In primary care, agreement between the patient's and GP's assessment on the prevalence of physical symptoms is acceptable,[4] but it is likely that GPs did not register all the symptoms affecting these patients. Hence, it is likely that patients had other symptoms that did not result in a registration or in a patient-GP encounter, and that the numbers of symptoms-related encounters we found are underestimations of total

symptom prevalence in patients receiving end-of-life care at home. Nevertheless we may presume that the symptoms registered in the electronic medical records represent the most important symptoms for both the patient and the GP.
The results had primarily a descriptive character. Hence, we lacked detailed information about the GPs' motivation for certain choices. An example of this is that we do no know why a GP-patient contact occurred or why GPs did or did not cooperate with other care providers. In this respect, we found important results, but these need to be interpreted carefully and this thesis evokes many new questions. Finally, we limited our longitudinal analyses to the three months prior to death. This was a practical consideration as we had to balance a maximum time-frame to indicate developments in disease and care trajectories against the inclusion of as many patients as possible.

Interviews
In our quantitative survey we investigated epidemiological issues, yet the viewpoints of both patients and their general practitioners regarding the quality of end-of-life care at home were unknown. In order to investigate the nature of the core values of patients and their GPs regarding end-of-life care, we conducted qualitative interviews with patients and their GPs. Strengths of this design were that we included both GPs with and without special interest in end-of-life care, and patients with cancer as well as non-cancer patients. The researchers were not involved in providing end-of-life care themselves and interviewed the patients and their GPs according to similar interview guides. We assured the patients that the information would remain confidential and that confidentiality was also assured for their GP.
Also, this qualitative data collection had some limitations. The GPs we interviewed confirmed that they had made a selection of patients who they thought were suitable to be interviewed. Some GPs did not approach patients if the GP-patient communication was difficult, and did not approach patients who were in an instable phase of their illness. Hence, we probably interviewed the patients who were relatively well and who were satisfied with their GP. Patients who are less satisfied and who are instable, might value different aspects. For example, in patients with a greater risk of poor symptom control, aspects such as achieving symptom control might be more important compared to availability of the GP or attention. Also, due to the presumably better patient-physician contact in the patients interviewed, subjects such as euthanasia might have been easier to talk about, and GPs might have been more sensitive in exploring the patients' signals. Furthermore, by interviewing these patients only once, we could not monitor any change in their opinions. Yet, given these limitations, we have the opinion that they did not substantially change our findings.

EPIDEMIOLOGICAL ISSUES OF END-OF-LIFE CARE IN GENERAL PRACTICE

Defining the patient population
To a population that died while they were receiving care from their GP, we applied three different criteria for end-of-life care, namely (1) non-curative treatment, (2) palliative care or (3) death was expected (chapter 2). This made it possible to compare similarities and differences between the selected sub-populations. The criterion 'death was expected' included most patients (62%) followed by 'palliative care' (46%) and 'non-curative treatment' (39%). Similarity between the three definition-based populations was fair to moderate. More 'palliative care' and 'death was expected' patients had cancer than

'non-curative treatment' patients, and the 'palliative care' population had more doctor-patient contacts.
The labeling of patients by a caregiver, may possibly influence patient care itself. In a study focusing on patients with colon and lung cancer, patients whose GP considered the care to be palliative died earlier than those whose GP did not.[5] This might indicate that the label 'palliative care' is associated with a more serious illness. Our study shows that the 'palliative care' population included patients who had more doctor-patient contacts than patients included by the other criteria, and that most of these patients had cancer. This supports the argument that palliative care is related to intensified care. However, the question is: do these patients receive the label 'palliative care' because they have cancer, or because they need and receive intensified care? If it is the first reason, patients with a chronic illness who are labeled as 'death was expected', but not as 'palliative care' patients, might possibly be excluded from receiving the more intensified care that they might need.
The findings of this study have implications for the understanding of the composition of populations included in end-of-life research. First, the overall distribution shows that there is little similarity between patient groups defined as 'end-of-life' patients. It also illustrates the extreme difficulty of defining groups in end-of-life research. Future research should focus on further investigation of the diversity in characteristics of end-of-life care populations. This is only possible if future studies describe in more detail the way in which their population is included. If we want to describe differences between sub-populations without omitting any potential end-of-life patients, we must apply the broadest possible inclusion criteria. Hence, we recommend the use of a combination of different inclusion criteria, which should include at least 'palliative care' as labeled by (professional) carers, the intention of the palliative care treatment provided, and an assessment of the patient's life-expectancy.

Needs of end-of-life patients: prevalence of symptoms
In the patients who died at home and who received care until death by their GP, digestive symptoms (59%), pain (56%) and psychosocial symptoms (45%) were most prevalent in the patient-physician encounters in the last three months of life (Chapter 3). Also, musculoskeletal symptoms (20%), chronic ulcer (18%) and requests for/ talking about euthanasia (14%) were prevalent. The mean number of encounters about any symptom in the last three months of life was higher in cancer patients (11.99) than in non-cancer patients (7.62). Also, in younger patients the prevalence of digestive symptoms, pain and psychological symptoms was higher than in the elderly. Most symptoms (36%) were concentrated in the last two weeks of life.
Our study confirms the results of other studies that also found that the prevalence of symptoms was higher in cancer patients and in younger patients.[6,7] Younger patients have more encounters about symptoms, which can be explained by the possibility that they can stay at home with a more severe disease because they have a reliable support system.[8] Another explanation is that older and non-cancer patients need fewer contact because they have a more mitigated disease trajectory.[9] Our study is based on symptoms registered during encounters, where most other studies measured symptoms that were prevalent using a list of possible symptoms, e.g. the Palliative care Outcome Scale (POS) or the Edmonton Symptom Assessment System (ESAS).[10,11] Hence, symptom prevalence might be underreported in our study.
However, the diversity of symptoms is probably larger: not reported in previous end-of-life studies were musculoskeletal symptoms and chronic ulcer. These are probably

typical examples of everyday problems encountered in general practice. This suggest that both typical end-of-life symptoms such as pain and digestive tract symptoms, and everyday symptoms influence the patient's quality of life.
In the last two weeks of life we found an increase in the symptoms that are prevalent (chapter 3). Also, we found a similar increase in the management of the symptom pain by prescribing pain medication (Chapter 4). This development occurs in cancer as well in non-cancer patients. This concentrations of symptoms in the last weeks before death strongly suggests that this development corresponds with the patient's needs for pain and symptom management. The exponential character of the prevalence of pain and symptoms has not been described in end-of-life populations in general practice, and is in contrast with the gradual development of symptoms in patients receiving end-of-life care in nursing homes.[12]

Quality of end-of-life care by the GP: prescribing of pain medication
In the DNSGP we were unable to ask patients directly about the quality of end-of-life care they received from their GPs, hence we measured indicators of quality of care in an indirect way (Chapter 4). Out of many aspects of quality in end-of-life care, we focussed on two specific indicators for quality of prescribing, namely (1) whether GPs prescribed analgesics according to the World Health Organization (WHO) analgesic ladder, and (2) if opioids were combined with laxatives. The WHO analgesic ladder is composed of three steps of pharmacological therapy: step 1 involves the analgesics paracetamol and nonsteroidal anti-inflammatory drugs (NSAIDs), step 2 opioids for mild to moderate pain (e.g. tramadol and codeine) and step 3 includes opioids for moderate to severe pain (e.g. morphine and phentanyl).[13] According to the same WHO guideline a laxative should be given when an opioid is prescribed. Our study showed that the prescribing of GPs differs considerably from these guidelines. Of the patients who were prescribed a step 1 analgesic, 40% was prescribed a step 3 opioid without having been prescribed a step 2 analgesic. A total of 60% of the non-cancer patients and 41% of the cancer patients was prescribed an opioid without any prescribed laxative, and 14% of all patients was prescribed a laxative three or more days after the start of the opioid.
In our study population, 27% of patients receiving end-of-life care at home, and 19% of the cancer patients, were not prescribed analgesics. Although pain is extremely common in cancer patients, studies report a wide variation in the prevalence of pain (33-88%).[14] The proportion of patients receiving a prescription for analgesics in our study, is comparable to numbers found in other studies.[14;15] Future studies need to investigate why these patients are not prescribed analgesics: because there is no need for pharmacological management of pain, or because GPs do not adequately manage pain.
Another result was that family doctors often skip the second step of the ladder. Although we have not collected data on the level of pain control, the exponential increase of prescriptions for strong opioids nearing the patient's death suggests a corresponding increase in pain. Our data imply that for the optimal management of pain, some patients might benefit from the omission of step 2 of the WHO analgesic ladder, as suggested by other authors.[17]
The proportion of patients who are prescribed laxatives as co-medication is low, although this combination is advised in most guidelines.[13,18,19] Possibly, prescribing co-medication is difficult to keep in mind for the GP, and this aspect needs more attention in education and/or collaboration with pharmacists.[20] On the other hand, it might also be that there is a substantial proportion of patients who will not benefit from the prescription of laxatives, and GPs in some way are able to discriminate between patients. The question

of whether laxatives need to be prescribed to all patients using opioids, is even more important to the non-cancer patients as 60% of them do not receive the laxatives they might benefit from.

Organisation of end-of-life care at home: cooperation between GPs and other caregivers

In almost all cases of patients receiving end-of-life care at home in the Netherlands, the GP cooperated with at least one other caregiver, with a mean number of four collaborators (Chapter 5). In patients receiving end-of-life care, GP cooperation with other caregivers is highly prevalent, with informal caregivers and other primary caregivers the most common. The best determinants for cooperation between GPs and other caregivers were the patient's age, the underlying disease and the importance of psychosocial care in the care for the actual patient. Cooperation was more prevalent in younger patients, patients with cancer as underlying disease, and when psychosocial care was important. With a mean of four collaborators for each patient receiving end-of-life care, GPs reflected the goal of end-of-life care as a multidisciplinary approach.[21] In most patients the GP works with one collaborator at a level labelled as intensive, and in most cases this was the informal caregiver or the district nurse. However, with the aim of directing end-of-life care at 'the patient and their family'[21] cooperation with informal caregivers can be improved to meet the concerns of both patients and their informal carers.[22] In about two thirds of patients GPs cooperated with district nurses (DNs). This was not considered to be a low figure, as DNs are involved with more serious physical and psychosocial problems, or when technical bedside expertise is needed.

GP cooperation with colleague GPs was only present in about half of the patients. We consider this low as patient information is expected to be handed over after office hours. In the Netherlands over 90% of the population is covered by out-of-hours cooperatives.[23] It is possible that GPs care for their terminally-ill patients themselves, or that GPs do not define handing over patient information as cooperation. Although this needs future exploration, it does question the quality of communication and continuity by the GP during out-of-office hours, a difficult area in end-of-life care at home.[24]

The most striking determinant of GP cooperation with other caregivers was the importance of psychosocial caring in care for the actual patient. This finding is difficult to interpret, as we have no data on the content of the collaboration. An explanation may be that the nature of the psychosocial problems itself may demand more communication and coordination[25], or that the prevalence of psychosocial problems is intertwined with somatic issues.[26] This suggests that communication is not only important in the patient-GP relationship, but also in contacts with other care providers.

OPINIONS OF PATIENTS AND THEIR GPs

Good end-of-life care

Patients and GPs identified the same four core aspects as most valued in end-of-life care: availability of the GP for home visits and after office-hours; medical competence and cooperation with other professionals; attention; and continuity of care (Chapter 6). These values were identified and agreed upon by both patients and their GPs, and by cancer patients as well as by non-cancer patients.

The aspects valued in end-of-life care are comparable with those found in chronically ill patients.[27,28] Some authors have tried to combine the results from different studies in a

conceptual framework for good end-of-life care. Stewart *et al*. identified in their quality of life model three factors that affect quality of life in terminal care: (1) fixed patient and family factors, not amenable to change (2) structure and process factors, and (3) outcome factors (Figure 1).[29]

PATIENT FACTORS AFFECTING HEALTH CARE AND OUTCOMES OF CARE	STRUCTURE AND PROCESS OF CARE		OUTCOMES OF CARE	
PERSONAL AND SOCIAL ENVIRONMENT ■ Patient and family situation ■ Clinical status, casemix ■ Social support for patient ■ Social support for family	STRUCTURE OF CARE ■ acces to care within system ■ organization of care ■ Formal support services available ■ Physical environment(s) of care	PROCESS OF CARE WITH PHYSICIANS, NURSES, SOCIAL WORKERS ■ Technical process with patient ■ Decision-making process with patient and family ■ Information, counseling of patient and family ■ Interpersonal and communication style with patient and family	SATISFACTION WITH HEALT CARE ■ Patient satisfaction with care ■ Family satisfaction with care	QUALITY AND LENGTH OF LIFE ■ Quality of life of patient ■ Quality of life of family and loved ones ■ Quality of dying of patient ■ Length of life

Figure 1.
Overall conceptual model of factors affecting quality and length of life of dying patients and their families. (Used from Stewart *et al*.)[29]

The aspects mentioned by the patients and GPs in our study are also present in Stewart's model. Availability of the GP for home visits and medical competence are part of the categories of structure and process of terminal care. Attention is related to communication and interpersonal skills, which are elements of the process of terminal care. Continuity is also included with the (technical) process factors. The aspects we found are all at the level of structure and process of care; we found no outcome-related aspects of good end-of-life care.

In our study potential results of GP interventions, such as less pain or better symptom control, were emphasised less than was the availability of the GP. One reason might be that patients expected that GPs, in the patients' opinion medically competent, would achieve good control of pain and symptoms; alternatively the lack of outcomes mentioned by patients might be because they considered the importance of outcomes to be obvious. It might also be the opposite: the failure of health care to cure their illness, may possibly have led to low expectations with regard to outcomes of care at home. Future studies should investigate how different domains in end-of-life care are related and interact.

Communication about euthanasia

Communication about euthanasia does not always mean that the patient has an actual request for euthanasia (Chapter 7). Patients prepare themselves for a (worst case) scenario in which they might consider euthanasia. At the same time, GPs are also anticipating their (worst case) scenario: a situation in which they are requested to administer lethal

drugs. GPs had different opinions about whether they should initiate communication on euthanasia, and found it difficult to judge the right moment to start talking about it. Also when their GP started talking about euthanasia, patients expressed their own opinions in favour as well as against euthanasia.
In this study, most of the GPs were cautious, and some were even reluctant to initiate communication about euthanasia, and approximately half of the patients communicated with their GPs on this subject. In the context of euthanasia as one of the end-of-life options, we had expected more communication. We also expected that more GPs would have initiated communication, because patients should be informed about all possible options to enable them to make informed end-of-life decisions.[30] It seems that the legality in the Netherlands of euthanasia does not make it easy to initiate communication about this subject. GPs might fear that starting to talk about it will increase the possibility that the patient will actually request euthanasia, but this was not mentioned by our patients or GPs. In our opinion, open communication may result in agreement between patient and doctor on whether or not to perform euthanasia.

IMPLICATIONS OF THE RESULTS

In this thesis we presented answers to some questions about issues in end-of-life care in general practice. Also, this thesis raised new questions. By discussing some of the implications of these answers and questions, we want to stimulate further research, improvement of practice and development of policy concerning end-of-life care.

Implications for further research

In our qualitative study we found four core values of good end-of-life care in general practice: availability of the GP for home visits and after office-hours, medical competence and cooperation with other professionals, attention and continuity of care (Chapter 6). Although these are core values according to patients and their GPs, due to the selection bias in this small-scale qualitative study, we have to be careful to generalise these findings. Patients not included in our study, might value different aspects as core values. Hence, to assess good end-of-life of care in general practice, we need to confirm our qualitative findings in representative patient populations.
We have studied three epidemiological issues of end-of-life care in general practice: needs of patients receiving end-of-life care, quality indicators of end-of-life care delivered by the GP, and cooperation in organisation of end-of-life care at home (Chapters 3, 4 and 5). We found associations between patient characteristics and patient's needs, quality of care and organisation, however, we were unable to measure outcomes of care. The study design was not directed to examine end-of-life care. Hence, it was not possible to investigate relations between symptoms prevalent in patients, symptom management by the GP, achieved symptom control, and the specific contributions of the caregivers involved. To investigate aspects of quality of end-of-life care in general practice in more detail, future studies should be designed to examine these relations between patient characteristics, symptoms prevalent in patients, care provided by GPs, achieved symptom control and cooperation between different care providers.
The epidemiological issues we examined were related to quality of end-of-life care. Symptoms that were prevalent, may indicate a need for symptom management (Chapter 3). Non-compliance to guidelines of prescribing might mean that patients were not treated well (Chapter 4), and few other caregivers that cooperated with the GP could

mean that knowledge and experience of other caregivers does not contribute to the end-of-life care of the patient in question (Chapter 5). These issues, however, do not measure whether the care provided by the GP was sufficient, or how end-of-life care at home might be improved. Therefore, we should first be able to measure quality of care, and changes in quality of end-of-life care.[31] When do we consider end-of-life care at home as good? Indicators of quality of care could be defined as 'measurable elements of practice performance for which there is evidence or consensus that it can be used to assess the quality, and hence the change in the quality of care provided'.[32] However, these indicators are not yet well developed in end-of-life care and future research should be directed to developing more valid, reliable and responsive quality indicators for end-of-life care at home.

The development of quality indicators for end-of-life care is complex, and faces three major challenges. First, there is a lack of measurable elements of practice performance. Second, it is difficult to determine what is 'good' end-of-life care. Third, interpretation of scores on quality indicators can be problematic, certainly in end-of-life care.

A lot of possible indicators for quality in end-of-life care have been suggested with regard to the first challenge: the development of measurable elements. Some authors have ordered these indicators into comprehensive models, with models of Emanuel and Emanuel, and the model of Stewart showed in Figure 1 on page 103 as examples of such an approach.[29,33] However, for only a few of the aspects, validated instruments have been developed to measure them.[34] Future research should first aim to develop a comprehensive set of validated instruments for the measurement of relevant concepts in end-of-life care.

But even with the availability of good instruments to measure the relevant concepts, we face a second normative and conceptual challenge: the task of defining the desired level of care. How, and from whose perspective, do we define what is 'good' in end-of-life care? This challenge is complex because end-of-life care is directed at the 'improvement of the quality of life of patients and their families'.[21] Due to the incorporation of the perspective of both the patient and his family, the determination of the goals in the actual care is reached by a process of shared decision making between the patient, the family and the GP. It may be that the professional opinion of the GP will conflict with individual preferences of patients and/or families.[35] The complexity of problems in end-of-life care and the importance of the patient, the family and the professional perspective, might make it more difficult to assess the desired level of quality, compared with other fields of medicine, where it is easier to predict the outcomes of shared decision making. This second challenge asks future studies to determine what is 'good', and to find ways to incorporate both professional knowledge and the perspective of the individual patients and their families in quality indicators of end-of-life care.

The irregular course of illness trajectories at the end-of-life is a third challenge in measuring the quality of care at the end of life (Chapters 3 and 4). It might be that initial goals determined for certain aspects of an individual patient's care will not be achieved although optimal quality of care has been given. Reasons for this could be that the progress of the disease will have a more negative effect on certain outcomes, than the positive effect of intervention(s). Also, goals can be changed because priorities in care may shift throughout the disease trajectory. This illustrates that quality indicators in end-of-life care need to be responsive to changing circumstances, hence future research should also take into account this perspective when determining quality indicators.

In conclusion, future research has to develop quality indicators to assess and improve

the actual quality of end-of-life care. Only with a good set of quality indicators, we will be able to measure the quality of end-of-life care at home and compare it with care settings, and to monitor changes in quality over time in relation to developments in demographics and the performance and organisation of end-of-life care.

Practice implications

The studies performed as part of this thesis have some implications for the practice of end-of-life care at home. We will discuss how the four core aspects found as most valued in end-of-life care might influence daily practice. Also, we will examine the consequences of the complex character of end-of-life care and the knowledge and skills that are needed in the care of the terminally-ill. Furthermore, we will talk about the role of the GP in relation to patients who need spiritual care and communication about euthanasia. Finally, we will discuss the possible implications for cooperation with other care providers in primary care.

The four core aspects found as most valued in end-of-life care were availability of the GP for home visits and after office-hours; medical competence and cooperation with other professionals; attention; and continuity of care (Chapter 6). We did not investigate how GPs were able to perform end-of-life care and what problems they encountered. However, GPs might incorporate the aspects found as most valued in end-of-life care in the organisation of their activities. Home visits might be planned in advance, and patients might be given information on who will be available during out-of-office hours, when the GP is not available himself. GPs should make sufficient time for home visits to give patients attention and to allow them to talk about their most important concerns. An essential condition to cooperate with other caregivers is that GPs need to know how and when they can reach these caregivers. It should also be clear how information between the patients, the GP and other caregivers will be transferred. When personal continuity by one GP cannot be achieved, it should be clear for the patients and other caregivers which GPs are involved in end-of-life care and who is responsible. In conclusion, anticipation and communication on aspects valued in end-of-life care, may bring the patient and the GP clarity and peace, and hence contribute to the quality of end-of-life care.

GPs encounter a wide range of problems in patients receiving end-of-life care in general practice, and cooperate with many other caregivers (Chapters 3 and 5). Some problems are specific to end-of-life care such as pain and digestive tract symptoms, while other are also typical problems in a common population of the elderly, such as musculoskeltal problems and chronic ulcer. Management of symptoms in terminally-ill patients can sometimes be complex. At the same time GPs do not care for that many patients at the end of their life. Hence, they build up their experience over years, and need to be supported by specialised knowledge, e.g. by access to a colleague who is (better) trained in end-of-life care. In this respect, the support of a consultation team, and the training of GPs or other physicians with specialised knowledge in end-of-life care are essential to safeguard good end-of-life care provided by the GP at home.

Not only pain and physical symptoms require special attention; psychosocial and spiritual issues are also part of end-of-life care. Our study showed that with regard to patients in whom psychosocial and spiritual issues are important in end-of-life care, GPs more often cooperate with colleagues (Chapter 5). As they hardly cooperate with social workers and spiritual caregivers, GPs probably deal with these problems themselves, or entrust this care to other caregivers not specifically trained in these issues such as district nurses (DNs). Also possible is that it is not seen as the GP's task to provide spiritual or social care,

or the GPs may not recognise or respond adequately to patients with these problems. In conclusion, GPs need to pay attention to the possibility of psychosocial or spiritual care needs in each patient, and communicate with the patient and the caregivers involved who will care for these needs.
As hastening death is a legalised option within medical practice in the Netherlands, it is essential to pay more attention to training in communication about death, dying and euthanasia. Guidelines, as being developed in Belgium, may support the GP's need to find answers to their individual questions.[36] Although euthanasia is only legalised in a few countries, this does not mean that patients in other countries do not have a need for doctors who communicate well about difficult end-of-life decisions also. Communication about end-of-life preferences will allow GPs to direct care for the individual patient towards the best possible quality of life and quality of dying.
Finally, the quality of life may also be enhanced by more cooperation with other care providers. Given the complexity of end-of-life care and the diversity of problems that may require attention, the involvement of all necessary disciplines must be encouraged and facilitated. On the other hand, the number of caregivers needs to be limited because patients and family prefer continuity of care with a few caregivers[37], and patients and family caregivers are often reluctant to accept help from others than their own GP. One of the caregivers involved in end-of-life care must be responsible for the organisation of the involvement of all relevant disciplines. In end-of-life care at home, GPs or DNs could perform this task[38], however there is still discussion on who should be in charge.[39-41] For the patient, this is less important as long as a competent caregiver performs this task. The same goes for prescribing optimal drugs. We have shown that not all GPs follow accepted guidelines. First, as we have discussed in the previous section, this could mean the guidelines do not comply with the best quality of care and GPs have developed this knowledge somehow in their practice. To perform optimal pharmaceutical end-of-life care, we would encourage GPs and pharmacists to cooperate and attune their practices. One promising development in health care organisation is the development of the Electronic Patient Record, in which health care providers can register patients' needs, interventions and outcomes.[42] When privacy issues will be adequately addressed, this is a promising tool to support continuity, cooperation and communication between all health care providers involved in end-of-life care.

Implications for policy

Our study does raise some questions about the quality of future end-of-life care at home. Aspects valued in our study might be subject to transitions in demographics and primary care which will change the size and structure of the population, the care at home and the role of the GP. The population in the Netherlands is ageing, with an expected maximum of four million inhabitants aged over 65 in 2040, compared to the current 2.5 million.[43] In the ageing society, the number of deaths will increase with a growing demand for end-of-life care as a result. Meanwhile, the structure and goals of primary care will change: the relative number of care-givers decreases, while GPs will work more frequently in primary care cooperatives and more GPs will work part-time.[44]
The current role of the GP in end-of-life care, and the core values of good end-of-life care according to patients and their GPs, might be threatened by these developments. First, we will discuss the implications of future changes in the organisation of GP care, and second we will put forward some questions that need to be addressed politically in order to anticipate these future developments.
First, in primary care there are developments favouring more part-time jobs, wider career

possibilities, fewer solo practices and less local cooperation of GPs, especially with respect to after office-hours services.[44-46] This could become a threat to the personal continuity of care and after office-hours services for end-of-life care patients.[47-48] It will be more difficult to organise personal continuity for part-timers, especially after office-hours. The wider career possibilities will make it easier for GPs to move to other practices during their careers, and this will also decrease the duration of patient-doctor relation.[46] Large-scale organisation of after office-hours services by GP cooperatives will probably not only decrease the number of visits after office hours, but will also imply that these visits will be made by a GP who is unfamiliar with the patient and the family.

Second, the government has to anticipate these developments in order to organise and finance the care that will be needed. Can we make dying at home possible for all patients, and if not, for which patients do we want to make dying at home accessible, and for which patients we do have to organise good end-of-life care in another setting? And when we look at those aspects of end-of-life care which are most highly valued, such as home visits and attention, how much care should be provided? How will we determine the difference between comfort and care? And when discomfort, symptom burden or loneliness eventually contribute to a low(er) quality of life, whose responsibility is it to organise care and/or comfort for this patient? To determine 'quality' in future end-of-life care at home, and the responsibilities of the patients and the caregivers involved, we need continuing attention and discussion within society. That discussion is needed in order to direct future developments of end-of-life care at home, and the position of the GP.

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SUMMARY

SUMMARY

In the Netherlands, the general practitioner (GP) is the central professional in the management and coordination of the patient's treatment. Almost 60% of the patients with non-acute illnesses die at home, and there is a general consensus that end-of-life care, if possible, preferably should be provided in the patient's home. The actual and formal approach of the Dutch government is that end-of-life care should be provided as much as possible by generalists, and in this context initiatives to make possible the responsible, complex and demanding tasks of providing end-of-life care were stimulated. Because few studies have been performed in order to describe and understand the role of the GP, end-of-life care research activities concerning general practice were initiated. This thesis aims to investigate issues of current practice in end-of-life care in general practice in the Netherlands.

In this study, the following research questions were addressed:

- 1. What are the consequences of using different inclusion criteria on selected end-of-life care populations?
- 2. What is the prevalence of pain and other symptoms in patients receiving end-of-life care at home?
- 3. What pain medication is prescribed to patients receiving end-of-life care at home?
- 4. What is the extent and the level of GP cooperation with other caregivers in end-of-life care at home?
- 5. What are the aspects valued in end-of-life care at home by patients and their general practitioners?
- 6. Do patients talk about euthanasia with their GP and if so, how do they communicate about this subject?

For this thesis, data from two different studies were used. Quantitative data were collected within the framework of the Second Dutch National Survey of General Practice (DNSGP-2), a representative sample of 96 Dutch general practices, and qualitative data were obtained by interviews with 30 patients and their GPs.

Defining the patient population

In preparing the research of this thesis, we encountered the problem that there is no generally accepted research definition of end-of-life care, and that there is no general consensus what criteria to use for inclusion of patients. Chapter 2 investigates the consequences of three inclusion criteria in the build up of different study populations, studied in terms of size, number of doctor-patient contacts and demographic characteristics. General practitioners received a questionnaire for all patients who died during the DNSGP-2 (n=2,194), to determine whether (1) patients received non-curative treatment, (2) patients received palliative care, and (3) death was expected (total response rate=73%). The criterion 'death was expected' included most patients (62%) followed by 'palliative care' (46%) and 'non-curative treatment' (39%). Similarity between the definition-based populations was fair to moderate. More 'palliative care' and 'death was expected' patients had cancer than 'non-curative treatment' patients. The conclusions show substantial differences in populations according to the different inclusion criteria used to select them. If we want to describe differences between sub-populations without omitting any potential palliative care patients, we must apply the broadest possible inclusion criterion. Hence, we recommend the use of a combination of inclusion criteria, which should include at least 'palliative care' as labeled by (professional)

carers, the intention of the treatment provided, and an assessment of the patient's life expectancy. Any future research in end-of-life care should acknowledge the limitations of using certain inclusion criteria and explore potential bias.

Epidemiological issues

The main aim of this thesis is to study epidemiological issues of end-of-life care in general practice: needs of patients receiving end-of-life care, quality of end-of-life care delivered by the GP, and organisation of end-of-life care at home. As indicator for the patients' needs, Chapter 3 aims to study the prevalence of symptoms in patients receiving end-of-life care at home. Within the framework of the DNSGP, GPs identified those patients who received end-of-life care out of all patients who died within the one-year survey period (valid response rate 73%). Patients with an observation period of at least three months, and who received end-of-life care by their GP until death were included (*n*=429). Information regarding encounters during the last three months of life was derived from the electronic medical records kept by the GPs. A symptom was prevalent when it was registered by the GP in a patient-physician encounter. Digestive symptoms (59%) and pain (56%) were the most prevalent. The mean number of symptoms was higher in cancer patients (11.99) than in non-cancer patients (7.62). The number of digestive symptoms, pain and psychological symptoms was higher in the lower than in the higher age groups, and higher in cancer than in non-cancer patients. Most symptoms (36%) were concentrated in the last two weeks of life. Not reported in previous end-of-life care studies were musculoskeletal symptoms (20%), chronic ulcer (18%) and discussion about euthanasia (14%). Future studies should explore the severity and influence on quality of life of these lesser known symptoms in end-of-life care.

As indicator for the quality of care, we examined what pain medication is prescribed to patients receiving end-of-life care at home, and determined the longitudinal development of prescribing during the last three months of life (Chapter 4). We also investigated whether GPs prescribed analgesics according to the WHO ladder, and if opioids were combined with laxatives. Within the framework of the DNSGP-2, GPs identified patients who received end-of-life care out of all patients who died within the one-year survey period (response-rate 74%). We analysed prescribing data of analgesics, laxatives and antiemetics of patients with an observation period of at least three months (*n*=425). Of these patients, 73% were prescribed any analgesic; 55% were prescribed a step 1 drug of the WHO ladder (paracetamol, NSAIDs), 21% a step 2 drug (weak opioids), and 51% a step 3 drug (strong opioids). More younger than older patients were prescribed a strong opioid, and more cancer than non-cancer patients were prescribed a drug from all three steps of the WHO ladder. The proportion of patients having been prescribed a step 1 or 2 drug increased gradually and the proportion of patients having prescribed a step 3 drug increased exponential nearing the patient's death. Of those who were prescribed a step 1 analgesic, 40% was prescribed a strong opioid without having been prescribed a step 2 analgesic. A total of 48% was prescribed an opioid without any prescribed laxative. Current practice concerning the use of the WHO analgesic ladder and the prescribing of laxatives differs substantially from accepted guidelines. Future research should investigate these guidelines, and find evidence for a two step, or a three step strategy in the pharmacological management of pain in end-of-life care, and determinants for the need to prescribe laxatives next to opioids.

As an indicator of organisation of end-of-life care, Chapter 5 studies the occurrence and determinants of such cooperation in end-of-life care at home. For each patient

who died during the DNSGP-2, the relevant GP was surveyed on end-of-life care issues by an additional mail questionnaire. Of all patients, 2,194 (0.6%) patients died during the study period. GPs returned 1,771 (73%) of the additional questionnaires. According to the GPs 743 (46%) of their patients received end-of-life care. In almost all patients (98%), the GP cooperated with at least one other caregiver, with a mean number of 3.8 others. Cooperation with informal caregivers (83%) was most prevalent, followed by cooperation with other GPs (71%) and district nurses (63%). The best determinants for cooperation between GPs and other caregivers were the patient's age, the underlying disease and the importance of psychosocial care in the care for the actual patient. Cooperation is more prevalent in younger patients, patients with cancer as underlying disease, and if psychosocial care is important in care for the actual patient. Future research should focus on the underlying problems that need cooperation, how caregivers communicate, and what possible barriers they meet.

Opinions of patients and their GPs

In this thesis, we also aim to explore the opinions of two subjects involved: the patients and their GPs. In Chapter 6 the aspects valued by both patients and GPs in end-of-life care at home are explored. Qualitative, semi-structured interviews were performed with 20 GPs and 30 of their patients with a life-expectancy of less than six months, and with cancer, heart failure or chronic obstructive pulmonary disease as underlying disease. Patients and GPs had comparable perceptions of good end-of-life care. Patients and GPs identified four core items that they valued in end-of-life care: availability of the GP for home visits and after office-hours; medical competence and cooperation with other professionals; attention; and continuity of care. Future studies should monitor the developments in the organisation of primary care, such as the restriction of time for home visits, more part-time jobs and GP cooperatives responsible for care after office-hours in the context of these valued aspects in end-of-life care.

The aim of Chapter 7 is to explore if patients talk about euthanasia with their GP and if so, how they communicate about this subject. Qualitative, semi-structured interviews with 20 GPs and 30 patients with a life expectancy of less than six months, and with cancer, heart failure or chronic obstructive pulmonary disease as underlying disease were performed in primary care in the Netherlands, where euthanasia is legalised. In the GPs' perception, communication on euthanasia was more frequent in cancer patients. Initial communication between patient and GP concerned an exchange of opinions on possible situations for which euthanasia was desired. GPs had different opinions whether communication should be initiated by the patient or the GP, and found it difficult to schedule the right moment to talk about euthanasia. We found no evidence to believe that communication on euthanasia stimulates the patient to request euthanasia. When patients and GPs know each others opinions and expectations concerning end-of-life preferences, GPs might direct their care towards the best balance between the patient's quality of life, and the quality of death.

General Discussion

GPs encounter a wide range of symptoms in patients receiving end-of-life care. Some of these symptoms are typically for end-of-life care, other are common in a general patient population. To safeguard quality in end-of-life care, it is important that GPs can make an appeal to consultation services, and/or colleagues with specific training in end-of-life care. In patients receiving end-of-life care, GPs need to pay attention to the possibility of psychosocial or spiritual care needs, and communicate with the patients

and caregivers in question on this subject. Also, end-of-life care may be enhanced by more cooperation with other caregivers. We need evidence-based end-of-life interventions, as there is lack of evidence, and current practice differs substantially from accepted guidelines. There are no good studies regarding the effectiveness of step 2 (weak opioids) of the WHO analgesic ladder and the necessity of concomitant use of laxatives with opioids. We need well designed studies to answer these highly relevant questions.

Finally, our study does raise some questions about the quality of future end-of-life care at home. Aspects valued in our study might be threatened by social developments in primary care which might change the characteristics of care at home and the role of the GP. In primary care there are social developments towards more part-time jobs, wider career possibilities, less solo practices and more cooperation of GPs in GP cooperatives. These developments could become a threat for the personal continuity of the GP and after office-hours services for end-of-life care patients. As a consequence, the Dutch health care system is challenged to make choices in the management of the dying, and of the wishes of the dying in our society. Can we make dying at home possible for all patients, and if not, for which patients do we want to make dying at home accessible, and for which patients we have to organise good end-of-life care in another setting? When we look at those aspects of end-of-life care which are most highly valued, such as home visits and attention, how much care should be provided? When discomfort, symptom burden or loneliness eventually contributes to a low(er) quality of life, whose responsibility is it to organise care and/or comfort for this patient? To determine 'quality' in future end-of-life care at home, and the responsibilities of the patients and the caregivers involved, we need continuing attention and discussion within society. That discussion is needed in order to direct future developments of end-of-life care at home, and the position of the GP.

SAMENVATTING

Zorg in de laatste levensfase in de huisartsenpraktijk in Nederland

In Nederland is de huisarts de centrale zorgverlener en het eerste aanspreekpunt voor medische zorg. Bijna zestig procent van de patiënten met een niet-acute aandoening overlijdt thuis en de meeste mensen geven er de voorkeur aan dat de zorg in de laatste levensfase in de thuissituatie wordt gegeven. De Nederlandse regering heeft het standpunt dat zorg in de laatste levensfase zoveel mogelijk door generalisten, zoals de huisarts, verleend moet worden. Tot nu toe is er weinig onderzoek gedaan dat zich specifiek richt op de rol van de huisarts in de zorg rond het levenseinde.

In dit proefschrift worden diverse aspecten van de huisartsenzorg in de laatste levensfase onderzocht. De volgende onderzoeksvragen komen in dit proefschrift aan bod:

- 1. Wat zijn de gevolgen van het gebruik van verschillende inclusiecriteria voor onderzoekspopulaties van patiënten die zorg in de laatste levensfase krijgen?
- 2. Hoe vaak komen pijn en andere symptomen voor bij patiënten die huisartsenzorg in de laatste levensfase ontvangen?
- 3. Welke geneesmiddelen worden voorgeschreven om pijn te bestrijden bij patiënten die huisartsenzorg in de laatste levensfase ontvangen?
- 4. In welke mate en met welke intensiteit werken huisartsen samen met andere zorgverleners bij de zorg voor patiënten in de laatste levensfase?
- 5. Welke aspecten van de zorg in de laatste levensfase worden gewaardeerd door patiënten en hun huisartsen?
- 6. Praten patiënten met hun huisarts over euthanasie en zo ja, hoe communiceren zij over dit onderwerp?

Om deze vragen te beantwoorden, werden gegevens uit twee verschillende onderzoeken gebruikt. De kwantitatieve data werden verzameld binnen de context van de Tweede Nationale Studie naar verrichtingen in de huisartsenpraktijk (NS-2), waaraan een representatieve steekproef van 96 huisartspraktijken heeft deelgenomen in de periode van 2000-2001. De kwalitatieve data werden verzameld in interviews met dertig patiënten en hun huisartsen.

Het definiëren van de patiëntenpopulatie

In de voorbereidingsfase van het onderzoek stuitten we op het probleem dat er geen algemeen geaccepteerde definitie bestaat van 'zorg in de laatste levensfase'. Ook bestaat er geen overeenstemming over welke criteria het beste gebruikt kunnen worden om patiënten te definiëren die 'zorg in de laatste levensfase' ontvangen. In hoofdstuk 2 hebben we onderzocht wat de verschillen in de omvang van de populaties, het aantal arts-patiënt contacten en de demografische karakteristieken van de patiënten zijn, wanneer de drie criteria voor zorg in de laatste levensfase worden toegepast. Deze criteria waren: (1) het levenseinde was volgens de huisarts verwacht, (2) de huisarts definieerde de zorg als 'palliatieve zorg' en (3) de patiënt ontving een behandeling die niet gericht was op genezing en ook niet op levensverlenging. De huisartsen kregen een vragenlijst voor elke patiënt die overleed tijdens de NS-2 (n=2194) om te bepalen of de drie criteria bij de zorg voor de betreffende patiënt van toepassing waren. De totale respons op de enquête was 73%. Het criterium 'het overlijden was verwacht' was op de meeste patiënten van toepassing (62%), gevolgd door 'palliatieve zorg' (46%) en 'een behandeling niet gericht op genezing of levensverlenging' (39%). De overeenstemming

tussen de op deze criteria gedefinieerde populaties was matig tot gemiddeld. In de populaties gedefinieerd als 'palliatieve zorg' en 'het overlijden was verwacht', waren meer patiënten met kanker dan bij de patiënten die 'een behandeling ontvingen die niet gericht was op genezing of levensverlenging'. Er waren substantiële verschillen tussen de populaties geselecteerd volgens deze drie criteria. Wanneer we in epidemiologisch onderzoek bij patiënten in de laatste levensfase verschillen tussen subpopulaties willen beschrijven zonder hierbij patiënten te missen, dan moeten we een zo breed mogelijk inclusiecriterium gebruiken. Daarom raden wij een combinatie van criteria aan met tenminste de volgende inclusiecriteria: 'palliatieve zorg', zoals aangegeven door de betrokken zorgverleners in combinatie met criteria gebaseerd op de intentie van de behandeling en de inschatting van de levensverwachting van de patiënt. Keuzes voor bepaalde inclusiecriteria beïnvloeden de samenstelling van de onderzoekspopulatie. Daarom dient men bij onderzoek naar zorg in de laatste levensfase ten minste de beperkingen van het gebruik van bepaalde criteria te beschrijven en te exploreren hoe de gemaakte keuze voor criteria de onderzoeksresultaten zal beïnvloeden.

Symptomen in de huisartsenpraktijk

Een belangrijke doelstelling van dit proefschrift is om enkele epidemiologische aspecten van de palliatieve zorg in de huisartsenpraktijk te onderzoeken. Dit zijn de behoefte aan zorg voor patiënten die palliatieve zorg van hun huisarts ontvangen, de kwaliteit van de palliatieve zorg en de organisatie van palliatieve zorg in de huisartsenpraktijk. In hoofdstuk 3 wordt een indicator voor de behoefte aan zorg van patiënten in de laatste levensfase beschreven. Hierbij hebben we gekeken naar het vóórkomen van symptomen bij patiënten in de laatste levensfase in de huisartsenpraktijk. De huisartsen die deelnamen aan de NS-2, hadden de patiënten geïdentificeerd die palliatieve zorg ontvingen en zijn overleden binnen de periode van één jaar waarin de NS-2 plaatsvond (respons = 73%). Patiënten die palliatieve zorg ontvingen en tenminste drie maanden na de start van de NS-2 zijn overleden, werden opgenomen in dit onderzoek (*n*=429). De benodigde informatie over de huisarts-patiënt contacten tijdens de laatste drie maanden van het leven van de patiënt werd gehaald uit de Electronische Medische Dossiers van de huisartspraktijken. Een symptoom was aanwezig wanneer het als zodanig geregistreerd was door de huisarts. Symptomen gerelateerd aan het maagdarmkanaal (59%) en pijn (56%) kwamen het meest voor. Het gemiddeld aantal symptomen per patiënt was groter bij kankerpatiënten dan bij patiënten zonder kanker (11,99 vs 7,62). Het aantal symptomen aan het maagdarmkanaal, pijn en psychosociale symptomen was op jongere leeftijd groter dan op oudere leeftijd. Ook bij kankerpatiënten was dit aantal groter dan bij patiënten zonder kanker. De meeste symptomen (36%) traden op in de laatste twee weken voor overlijden. In andere onderzoeken komen symptomen aan het bewegingsapparaat (20%), chronische huidzweren (18%) en gesprekken over euthanasie (14%) niet voor. Verder onderzoek zal de ernst van de symptomen en de invloed daarvan op de kwaliteit van leven moeten onderzoeken.

Voorschrijven van pijnmedicatie

Als indicator voor de kwaliteit van zorg, hebben we onderzocht welke pijnmedicatie is voorgeschreven aan patiënten in de laatste levensfase (hoofdstuk 4). We hebben bepaald hoe het voorschrijven zich gedurende de laatste drie maanden heeft ontwikkeld. Ook hebben we onderzocht in welke mate het voorschrijfgedrag van huisartsen overeenkomt met de pijnladder van de World Health Organization (WHO pijnladder) en of sterke, morfine-achtige pijnstillers (opioïden) gecombineerd worden met laxeermiddelen. Van

patiënten die tenminste drie maanden na de start van de studie zijn overleden, werden de voorschrijfgegevens van pijnmedicatie en laxeermiddelen geanalyseerd. In totaal kreeg 73% van de patiënten ten minste één pijnstiller voorgeschreven: 55% een pijnstiller uit stap één van de WHO-pijnladder (paracetamol of een onstekingsremmende pijnstiller (NSAID), zoals ibuprofen), 21% een pijnstiller uit stap twee (zwakke opioïden) en 51% een pijnstiller uit stap drie (sterke opioïden). Er waren meer jongere dan oudere patiënten die een sterk opioïd voorgeschreven kregen en er waren meer kankerpatiënten dan patiënten zonder kanker aan wie minstens één pijnstiller werd voorgeschreven. Het percentage patiënten dat een pijnstiller uit stap één of stap twee kreeg voorgeschreven, nam geleidelijk toe naarmate het levenseinde van de patiënt dichterbij kwam. Dichtbij het levenseinde nam het percentage patiënten dat een stap drie pijnstiller voorgeschreven kreeg exponentieel toe. Van de patiënten die eerst met één stap een pijnstiller behandeld werden, kreeg 40% in een later stadium een stap drie pijnstiller, waarbij de tweede stap van de WHO-ladder werd overgeslagen. In totaal kreeg 48% van de patiënten een opioïd voorgeschreven zonder dat daarbij een laxeermiddelen werd voorgeschreven. In de huisartsenpraktijk in Nederland wijkt het voorschrijfgedrag duidelijk af van de WHO-pijnladder. Huisartsen combineren opioïden niet altijd met laxeermiddelen, zoals geadviseerd wordt in richtlijnen voor palliatieve zorg. Het is belangrijk om nader onderzoek te verrichten naar de toepassing van deze richtlijnen. Zo kan worden aangetoond welke strategie van pijnbestrijding in de laatste levensfase beter is: een tweestaps of een driestaps strategie en welke factoren bepalen of een patiënt die opioïden gebruikt ook laxeermiddelen moet gebruiken.

Samenwerking van huisartsen met andere zorgverleners

Als indicator voor de organisatie van palliatieve zorg is in hoofdstuk 5 de samenwerking van huisartsen met andere zorgverleners onderzocht, evenals de invloed van diverse factoren op deze samenwerking. Huisartsen die deelnamen aan de NS-2 kregen voor elke patiënt die tijdens de studie overleed een vragenlijst toegestuurd over de zorg in de laatste levensfase. Van alle patiënten die deelnamen aan de NS-2 overleden er 2194 (0,6%) tijdens de studie en stuurden de huisartsen 1771 (73%) vragenlijsten terug. De huisartsen identificeerden 743 (46%) patiënten die palliatieve zorg kregen. In bijna alle gevallen (98%) werd samengewerkt met minstens één andere hulpverlener. Gemiddeld werd per patiënt met bijna vier andere hulpverleners samengewerkt. Samenwerking met mantelzorgers kwam het meeste voor (83%), gevolgd door samenwerking met andere huisartsen (71%) en wijkverpleegkundigen (63%). De drie factoren die samenwerking tussen huisartsen en andere zorgverleners het beste voorspelden waren de leeftijd van de patiënt, de onderliggende aandoening en de mate waarin psychosociale zorg van belang was bij de zorg voor de betreffende patiënt. Samenwerking kwam vaker voor naarmate de patiënt jonger was, de patiënt kanker had als onderliggende aandoening en als de psychosociale zorg van belang was bij de zorg voor de patiënt. Toekomstig onderzoek zal aandacht moeten besteden welke problemen die ten grondslag liggen aan de noodzaak tot samenwerking, de manier waarop de verschillende zorgverleners communiceren en de belemmeringen die zorgverleners ondervinden bij samenwerking.

Meningen van patiënten en huisartsen over goede palliatieve zorg

Dit proefschrift heeft ook tot doel om inzicht te krijgen in de mening van de patiënt in de laatste levensfase en zijn huisarts. In hoofdstuk 6 onderzoeken we welke aspecten patiënten en hun huisartsen waarderen in de zorg in de laatste levensfase. Hiervoor

hebben we kwalitatieve, semi-gestructureerde interviews afgenomen bij twintig huisartsen en dertig van hun patiënten. De patiënten hadden een levensverwachting van maximaal zes maanden met als onderliggende aandoening kanker, hartfalen of COPD (Chronic Obstructive Pulmonary Disease). Patiënten en huisartsen bleken een vergelijkbare visie te hebben op goede zorg in de laatste levensfase. Zij identificeerden de volgende vier kernwaarden van aspecten die zij het meest waarderen in de palliatieve zorg: (1) beschikbaarheid van de huisarts voor thuisbezoeken en buiten kantooruren; (2) medische competentie en samenwerking met andere professionals; (3) aandacht van de huisarts en (4) continuïteit van zorg. Verder onderzoek zal moeten uitwijzen in welke mate huidige ontwikkelingen in de huisartsenpraktijk, zoals minder tijd voor huisbezoeken, meer parttime werk en samenwerken in de vorm van huisartsenposten, deze kernwaarden van goede palliatieve zorg zullen bedreigen.

Meningen van patiënten en huisartsen over communicatie over euthanasie
In hoofdstuk 7 hebben we onderzocht of patiënten in de laatste levensfase met hun huisarts over euthanasie praten, en zo ja, wanneer dit het geval is en hoe zij over dit onderwerp praten. Hiervoor hebben we kwalitatieve, semi-gestructureerde interviews afgenomen bij twintig huisartsen en dertig van hun patiënten in Nederland, waar euthanasie is gelegaliseerd. Volgens de huisartsen kwam communicatie over euthanasie vaker voor bij kankerpatiënten. In de eerste gesprekken tussen huisarts en patiënt over euthanasie werden gedachten uitgewisseld over mogelijke situaties die aanleiding zouden kunnen zijn voor euthanasie. De huisartsen verschilden onderling van mening of dit onderwerp ter sprake zou moeten worden gebracht door de patiënt zelf of door de huisarts. Zij vonden het moeilijk om te bepalen wat het juiste moment was om dit onderwerp ter sprake te brengen. Wanneer patiënten en huisartsen op de hoogte zouden zijn van elkaars verwachtingen en wensen met betrekking tot zorg in de laatste levensfase, zouden huisartsen hun zorg beter kunnen richten op de optimale balans tussen kwaliteit van leven en kwaliteit van overlijden.

Discussie
Huisartsen komen veel verschillende symptomen tegen bij de zorg voor patiënten in de laatste levensfase. Sommige symptomen zijn typerend voor de laatste levensfase, andere zijn veel voorkomend in een (oudere) patiëntenpopulatie. Om de kwaliteit van zorg in de laatste levensfase te bewaken, is het van belang dat huisartsen specialisten op het gebied van palliatieve zorg kunnen consulteren. Bij de zorg voor patiënten in de laatste fase van hun leven, dienen huisartsen ook aandacht te besteden aan de mogelijke zorgbehoefte met betrekking tot psychosociale of spirituele aspecten. De palliatieve zorg in de thuissituatie kan versterkt worden door meer samenwerking tussen hulpverleners. Er is bovendien behoefte aan interventies die gebaseerd zijn op wetenschappelijk onderzoek. Deze onderbouwing ontbreekt en de huidige beroepspraktijk met betrekking tot het voorschrijven van pijnmedicatie verschilt substantieel van algemeen geaccepteerde richtlijnen. Er zijn geen goede studies met betrekking tot de effectiviteit van de tweede stap van de WHO pijnladder of studies naar de noodzaak van de combinatie van opioïden met laxeermiddelen. Om deze voor de dagelijkse praktijk relevante vragen te beantwoorden, moeten nieuwe onderzoeken worden opgezet en uitgevoerd.

Tot slot roept ons onderzoek enkele vragen op met betrekking tot de kwaliteit van palliatieve zorg in de toekomst. De waarden van palliatieve zorg die uit ons onderzoek naar voren komen, zouden kunnen worden bedreigd door ontwikkelingen in de organisatie

van de eerstelijns gezondheidszorg. Hierdoor zullen de kenmerken van de palliatieve zorg, zoals die nu door huisartsen gegeven wordt, veranderen. Huisartsen zullen vaker parttime gaan werken en korter op één werkplek blijven. Er zullen minder solopraktijken zijn en meer samenwerking tussen huisartsen die in diverse vormen onder één dak zullen werken. Deze ontwikkelingen kunnen betekenen dat er minder persoonlijke continuïteit in de huisartsenzorg zal zijn binnen en buiten kantooruren. Wij zullen enkele maatschappelijke keuzes moeten maken over hoe wij willen zorgen voor patiënten die zullen gaan overlijden in Nederland. Willen wij thuis overlijden mogelijk maken voor alle patiënten? Als dit niet zo is, welke patiënten krijgen dan de mogelijkheid om thuis te overlijden? En voor welke patiënten organiseren we zorg op een andere locatie? Hoe bepalen we hoeveel zorg we willen en kunnen geven en wanneer kijken we naar de aspecten in huisartsenzorg die het meest gewaardeerd worden, namelijk thuisbezoeken en aandacht? En als symptomen, ongemakken en eenzaamheid leiden tot een mindere kwaliteit van leven, wie is er dan verantwoordelijk voor het organiseren van de benodigde zorg? Om te bepalen wat wij onder 'kwaliteit' verstaan in onze toekomstige zorg en om de verantwoordelijkheden van de betrokken patiënten en zorgverleners in kaart te brengen, moeten we een maatschappelijke discussie blijven voeren. Deze discussie is noodzakelijk om richting te kunnen geven aan de toekomstige zorg voor patiënten in de laatste fase van hun leven en de rol van de huisarts daarbij.

Een woord van dank aan iedereen die mij de afgelopen jaren gesteund heeft. Direct bij het wetenschappelijk werk en tijdens momenten daarbuiten. Dit dankwoord is voor mij een herinnering aan de vele mensen, tegen wie je misschien best wel wat vaker 'bedankt' mag zeggen. Als je dit dankwoord openslaat, om wat voor reden dan ook, bedankt. In ieder geval voor de interesse in dit proefschrift – of ten minste het dankwoord daarvan.

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als grootste non-conformist bewonder ik het feit dat je nog steeds een corrupt Irakees voetbalteam onder je hoede hebt. Rolf: laten we vooral op zomerse vrijdagmiddagen van het gerimpelde uitzicht (of het biertje) op het Leidseplein blijven genieten. Chris, ben jij de volgende van ons die promoveert?

Rolf, door jou geniet ik minder van cheeseburgers, maar hebben we wel de sterren zien schitteren in de Crucible. Tynke, van serieuze gesprekken tot de zacht geperste sinaasappelsap van de Registratiekamer: we hebben een geweldige tijd gehad in de Marsstraat.

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Bedankt.

Sander

Curriculum vitae of Sander Borgsteede

Sander Diederik Borgsteede was born in Emmeloord, the Netherlands on November 13, 1973. He grew up in Lelystad, and completed his pre-university education at the Almere College in Kampen, 1992. Subsequently, he went to Groningen to study Pharmacy. During these years he also worked as a travel guide for Vinea youth holidays and as a teaching assistant for the Department of Social Pharmacy and Pharmacoepidemiology. In the same Department he performed his Master's thesis on 'Differences between clinical trials and daily practice' and a three-month project on 'Drug surveillance on Curaçao'. After obtaining an MSc in pharmacy in 1997, he worked one year for the Netherlands Asthma Foundation on 'The Dutch hypothesis in its scientific context: the development of a disease concept in pulmonology'. In August 2000 he obtained his Pharmacist's Degree and started a project on end-of-life care in general practice at the Department of Public and Occupational Health of the EMGO Institute, VU University Medical Center, Amsterdam. Since October 2002 Sander has combined research with daily practice in a community pharmacy in the Venser Apotheek, Duivendrecht. From 2005 onward he has also been working as a University Teacher at the Department of Clinical Pharmacology and Pharmacy of the VU University Medical Center. Since November 2006 he has participated in a project to improve drug information for patients who are being dismissed from the Sint Lucas Andreas Hospital, Amsterdam. He will defend his thesis 'End-of-life care in general practice in the Netherlands' on December 22, 2006.